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Project THANKS: A Socio-Ecological Framework For An Intervention Involving HIV Positive African American Women With Comorbidities

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ABSTRACT

HIV-positive individuals are living longer today as a result of continuing advances in treatment but are also facing an increased risk for chronic diseases such as diabetes, and hypertension. These conditions result in a larger burden of hospitalization, outpatient, and emergency room visits. Impoverished African American women may represent an especially high-risk group due to disparities in health care, racial discrimination, and limited resources. This article describes an intervention that is based on the conceptual framework of the socio-ecological model. *Project THANKS* uses a community-based participatory, and empowerment building approach to target the unique personal, social, and environmental needs of African American women faced with the dual diagnosis of HIV and one or more chronic diseases. The long-term goal of this project is to identify features in the social and cultural milieu of these women that if integrated into existing harm reduction services can reduce poor health outcomes among them.

Keywords: HIV; Chronic Disease; Comorbidities, African American; Women

INTRODUCTION

The toll of HIV/AIDS on women of color in the U.S. is a public health problem of epidemic proportions. The Centers for Disease Control (CDC) estimates the rate of new HIV infections to be higher among African American women compared to Whites and other races. In 2009 for example, African American women made up only 14% of the U.S. female population and yet accounted for 66% of new HIV cases among all women; additionally, substance abuse-related risk behaviors accounted for 47.6 percent of all HIV transmission in this population

(CDC, 2011). In 2010, African American women experienced the disease at a rate that was 20 times higher than White women, and 5 times higher than Hispanic women (CDC, 2012a). Recent estimates suggest a slow but gradual decline in new infection cases among women of color. African American women today account for 29% of the estimated new HIV infections among all adults and adolescents, representing a 21% decrease since 2008 (CDC, 2012b).

CDC further suggests that as a result of continuing advances in harm reduction and antiretroviral treatment, HIV-positive individuals are able to live longer today, and lead a quality of life with measurable health benefits (CDC, 2013). Unfortunately however, certain treatment medications for HIV such as protease inhibitors are associated with insulin resistance, glucose intolerance, and metabolic syndrome—a cluster of metabolic abnormalities that ultimately predispose these individuals to an increased risk for obesity and related conditions such as diabetes, cancer, hypertension, renal, and cardiovascular diseases (UNAIDS, 2011). While some medications can cause side effects such as nausea, vomiting, anorexia, and diarrhea making food intake difficult, others are known to result in eating patterns based on an increased cravings for sweets and carbohydrate-rich foods, replacement of foods that are rich in proteins and other nutrients with empty calorie beverages and other low nutrient-dense foods, and consumption of less than the recommended number of servings of fruits and vegetables, all of which increase the risk for chronic diseases in this group (Mangili, et al. 2006; Suter, 2004).

In examining the relationships between HIV, and diabetes and heart disease among substance abusers with and without HIV, the prevalence rates of these chronic conditions were significantly higher among those who tested positive and were receiving antiretroviral treatment (Haregu, et al. 2012). Further establishing the prevalence of comorbidities among HIV-positive people, research has shown that that regardless of treatment, there was a consistent pattern of increased risk for liver disease, renal disease, and overall multi-morbidity among substance abusers that tested positive for HIV compared to those that did not. A negative correlation between the number of CD4 cells and the risk for vascular, and pulmonary disease was established; a CD4 count less than 200 was associated with an increased risk for these diseases (Goulet, et al. 2007). The incidence of cancer was also found to be significantly higher in those infected with HIV compared with the general population (Patel, 2008). In a study among 54,780 HIV-positive people, significantly higher incident rates for anal, vaginal, Hodgkin lymphoma, liver, lung, melanoma, leukemia, oropharyngeal, colorectal, and renal cancers were found. Such findings have led to the suggestion that the immunosuppression resulting from HIV infection possibly makes some individuals more susceptible to additional diseases (Ballow, 2011). Ultimately, these conditions add to the health concerns of this population resulting in a larger burden of hospitalization, outpatient, and emergency room visits (Solomon, et al. 1998).

Although all individuals with HIV are at risk for chronic diseases, the unique biological and physiological changes that manifest during pregnancy and lactation place an increased demand for nutrients, putting women at a higher risk for developing cardiovascular disease and osteoporosis in later years compared to men (Rooney, et al. 2002). Impoverished African American women with HIV may be especially vulnerable to poor health outcomes associated with these conditions due to a multitude of contextual factors including limited resources, health care disparities due to racial discrimination and oppression, developmental histories marked by poor nutrition and disease, and psychosocial influences such as lack of self-efficacy, powerlessness, stigma, and feelings of social isolation (Adimora, et al. 2006; Hargreaves, et al. 2002).

Compared to other ethnic groups, African American women were more likely to experience economic hardships and report being unable to meet essential food and health-related expenses (Belle & Doucet, 2003). As a group, African American women were also less likely to be insured, more likely to receive care in less than optimal organizational settings (such as the emergency room), and experience lack of continuity in the health care received (Fiscella, et al. 2002). Lack of cultural competency in health care workforce, or geographically influenced barriers (lack of transportation or strenuous distances to nearest healthcare facility) compounds the negative influences of these diseases (Wyatt, 2004; Sanders-Phillips, 2002).

Emerging evidence from intervention science suggests that health promotion programs that are based on strategies targeting individual behaviors alone are unlikely to succeed unless the socio-cultural, psychological, and environmental context in which these behaviors occur and are reinforced are also considered (Kumanyika & Morrissink, 2006). Without an understanding of how these forces interact to impact health-seeking behaviors, public health policies and programs aimed at reducing health disparities are unlikely to yield desired effects (Campbell & Quintiliani, 2006).

In recent years, there has been an impressive repertoire of innovative interventions aimed at promoting health among marginalized groups including African Americans and Hispanics. These programs are based on theoretical foundations that emphasize upon the multiple levels of influence that can impact an individual's health (Cargill & Fenton, 2009; Robinson, 2008). According to the Syndemic Theory for example, substance abuse, violence, AIDS, and psychological symptoms can be conceptualized as a "syndemic of interconnected and inseparable influences" that, when placed within a disadvantageous socio-ecological context, interact to disproportionately increase the burden of disease in some groups (Romero-Daza, et al. 2003; Singer, 2010; Singer, 1996). These data suggest a need for interventions that place ethnic minority women's health outcomes in a broad ecological and cultural context, and address the underlying and competing influences of various factors on their health behaviors in an integrated manner.

The socio-ecological model has been recognized as a systematic and coordinated approach for understanding and reducing disease risks, particularly among underserved and vulnerable population groups (Oetzel, et al. 2006; Gregson, 2001). The model assumes that while individuals can develop the requisite willingness to sustain strict treatment requirements in a challenging context, they are more likely to do so within a comprehensive network that considers their individual (knowledge, attitudes and beliefs) as well as their interpersonal (social support and size of social networks), environmental (availability of relevant information and educational resources), and institutional (public health policies) needs (Smith & Christakis, 2008). Programs designed around the constructs of the socio-ecological model can be critical to improving health outcomes because by considering the dynamic and cumulative interplay between the various contextual factors, and by linking individuals' health behaviors with their unique life experiences, they help health professionals to deal with the specific obstacles to behavior change within a population group more effectively (Krieger, 2001). There appears to be a science knowledge gap however, in the testing and application of such a framework to address any health-compromising behaviors among African American women faced with the dual diagnosis of HIV and a chronic disease.

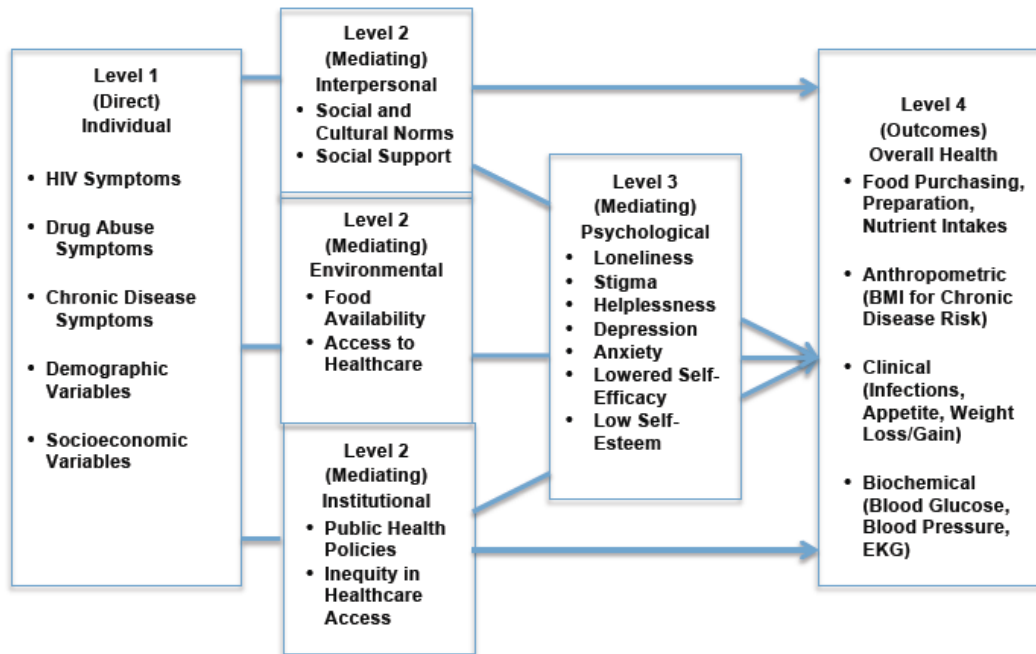
The Centers for Disease Control's Diffusion of Effective Behavioral Interventions (DEBI) programs includes several HIV prevention interventions that are specifically targeted

towards African American women with drug and alcohol dependency disorders. Programs such as SISTA and the Holistic Health Recovery Program (HHRP) include group-level intervention activities with well-defined standards of efficacy, and that have time and again demonstrated to be feasible for practical and cost-effective implementation in both clinical and community settings (Margolin, et al. 2003; DiClemente & Wingood, 1995). The curriculums include cultural and gender appropriate materials designed to give African American women a range of skills including negotiating and assertively communicating for personal safety and protection, managing HIV status disclosure decisions to their partners, managing stress through relaxation exercises, practicing safe sex, improving health seeking behaviors through a more active participation in their health care and medication adherence, and adopting other healthy lifestyle behaviors by eating a balanced diet and abstaining from drug use. However, these programs are largely based on models that focus on HIV and drug use, but do little to address the ways in which participants can proactively recognize symptoms and seek appropriate health care to manage the multiple complications associated with the dual diagnosis of HIV and another chronic condition such as diabetes, cancers, hypertension, and heart disease.

In recent years, significant associations between a higher body mass index (BMI) and obesity and multiple co-morbidities including diabetes and heart disease have been documented among ethnic minority female substance abusers living with HIV (Goltz, et al. 2012). While several initiatives exist to fund interventions incorporating nutrition care for HIV, a significant gap in programming exists that would address the multifaceted nutrition and lifestyle needs for women with HIV as well as diseases such as diabetes, heart disease, hypertension, cancer, and renal disease. Each disease has its own highly specific nutritional needs for maintenance and control; these factors, confounded with the limited healthcare directed towards the socioeconomically lower class and minority cultures, underscore the importance of priority setting in resource allocation, and developing contextually appropriate strategies that can be incorporated into existing HIV and substance abuse prevention programs serving these women.

The purpose of this article is to describe the rationale, need and procedures for an intervention that is based on the conceptual framework of the socio-ecological model (Figure 1). Project THANKS: Turning HIV/AIDS Into New Knowledge for Sisters uses a community-based participatory, and empowerment building approach as an effective and sustainable means to target the unique personal, familial, cultural, social, psychological and environmental needs of black female HIV-positive women faced with the dual diagnosis of HIV and one or more chronic diseases. By directly addressing the barriers leading to recidivistic behaviors, and by increasing the resolve to stay in treatment not only HIV but also for other chronic conditions and ailments, the project seeks to become more effective in ensuring overall positive health outcomes among HIV-positive African American women. The program components emphasize that HIV, substance abuse and chronic disease-related symptomology, low socioeconomic status, inadequate knowledge, lack of social support, insufficient neighborhood resources, low self-efficacy, and psychological distress from racial discrimination, stigma and marginalization, are all distinct yet intrinsically linked factors that must be considered together in order to understand how the conglomerate of these stressors may decrease the ability of African American women to meet essential healthcare needs.

Figure 1. Socioecological Conceptual Model for Project THANKS



Illustrated in Figure 1 are the pathways modeling the key factors we perceive as having a significant impact on the ability of African American women to simultaneously manage the multiple complications associated with having HIV and other chronic illnesses. Project THANKS is based on this model and defines these factors in terms of various intervention levels. For example, level 1 represents the direct influences of *individual factors* including HIV, substance abuse and chronic disease symptomology, and demographic, and socio-economic variables such as gender, race/ethnicity, poverty, income level, education, employment, and household composition. At level 2, the model assumes that the influence of the *individual factors* on their overall health outcomes is mediated by *interpersonal factors* defined by social and cultural norms, and social support for healthy eating, *environmental factors* defined as healthy food availability, and access to educational programs, health care services and resources, and *institutional factors* defined as effective public health policies ensuring equity in access to these services and programs. Level 3 represents *psychological factors* defined as psychological distress from stigma, depression, anxiety, and a lowered sense of self-efficacy. The model assumes that the influence of *interpersonal* and *environmental factors* on their health outcomes in this population is partially mediated by *psychological factors*. Finally, level 4 represents *overall health outcomes* defined by food choices (purchasing, preparing), food and nutrient intakes, body mass index (BMI; an indicator of chronic disease risk), and other clinical and biochemical parameters (blood glucose, blood pressure, EKG readings).

The intervention outlined was recently pilot tested at Well of Hope Community Development Center (WOHCDC) Inc., a harm reduction agency serving many low-income HIV-positive female substance abusers residing in and around Paterson, NJ. What follows in the sections below is a detailed description of the objectives and activities incorporated into the various sessions of the intervention, and the plans that are currently underway to evaluate the program's implementation feasibility, and the expected outcomes. We hope that the subsequent and greater use of this evidence-based framework will lead to more effective harm reduction

policies, and a minimization of the national health care costs associated with preventing and managing HIV and related comorbid conditions in this multiply vulnerable population.

METHODS

Program Design

Project THANKS uses the psychological and structural dimensions of empowerment to strengthen a participant's resolve to adopt healthy behaviors and to be an active participant in improving her own health. The program's culturally sensitive curriculum includes components that have been adapted from CDC's compendium of evidence-based HIV-prevention interventions for African American women, namely the Holistic Health Recovery Program (HHRP), and SISTA. Like these interventions, Project THANKS is built on a foundation of fostering a sense of community among African American women living with HIV. Such an approach to behavior change is particularly appropriate for this group because by emphasizing on sharing the responsibility of promoting good health between professionals and other non-professionals, the hope is that the women will feel more supported by their community, and consequently, empowered to be in-charge of their own health. The program differs from HHRP and SISTA however, in that in addition to HIV and substance abuse, this curriculum aims to provide women the necessary knowledge and tools to manage the complications associated with having multiple chronic illnesses more effectively.

Goals and Objectives: Project THANKS aims to teach women to live a healthy lifestyle in the following ways: 1) learn to prioritize their health care needs given the dual diagnosis of HIV and another chronic disease, 2) learn to recognize the symptoms of other chronic diseases early, and seek appropriate care, and 3) learn to become an active participant in their own health care by adopting healthy behaviors. Empowering them to stop using drugs and maintain an optimal health status despite the complications posed by substance abuse, HIV and related comorbidities requires establishing a firm foundation for participants to reaching success. The intervention aims to accomplish this goal by including components that enhance each individual's problem solving and decision-making skills, and build their sense of agency. Group-oriented facilitation techniques allow the delivery staff to work with the women in a supportive and shared small group setting. With the help of a trained facilitator, and peer leader, they are encouraged to engage in a dialogue with each other and reflect upon the personal, social, environmental, and political forces that impair their ability to access optimum medical, food, and exercise options, and create inequity across the health care continuum. The ultimate public health goal is to identify features in the social and psychological environments of HIV-positive black women with chronic diseases that if integrated into existing harm reduction services can help offset the human and economic costs of poor health in this multiply vulnerable population.

Setting

In New Jersey alone, women account for about one-third of the adult/adolescent HIV/AIDS diagnoses in the state. 86% of new diagnoses among women occurred in minorities and the rate of HIV/AIDS diagnosis among African American women was substantially higher than the rate among non-Hispanic White women. In Paterson, 92% of female HIV/AIDS cases are among Hispanic and black women. The primary modes of transmission among these women are heterosexual contact (53%) and injection drug use (39%) (Drug Policy Alliance Network, 2006). It is estimated that the state will continue to spend hundreds of millions of dollars each year on medical costs to treat the medical complications associated with HIV and related

diseases - costs that can be reduced through effective and comprehensive community-based services and education initiatives.

The Well of Hope Drop-in Center (WOHCDC), located in Paterson, New Jersey, was founded in 2002, as a mission of the Bethel AME Church in response to the needs assessment conducted by the Ryan White Task Force and the City of Paterson. Funded by the New Jersey Department of HIV/AIDS Services, the agency today offers a range of HIV Prevention and Care and Treatment services including the Minority AIDS Initiative that targets HIV infected Latino and African American individuals. In a limited-resource community setting such as WOHCDC, most clients receive healthcare and counseling. More than half of all the African American women currently served at this agency have substance abuse issues, and almost all of them are in outpatient substance abuse treatment. The most common substances used are cocaine, crack, heroin, alcohol, and marijuana. Most of these clients also suffer from other health ailments that affect their nutrition such as diabetes, heart disease, hypertension, cancers, Hepatitis A, B, and C, renal disease, intestinal bleeding, and asthma. Though highly effective interventions based on theories of behavior change have been developed in recent years to prevent and manage HIV, long-term efficacy--the maintenance of drug use recidivism and the prevention of chronic disease risks through durable health behavior changes--remains an elusive goal. Black women are labeled as especially 'hard-to-reach' or 'hidden', and therefore, most likely to be under-represented in program outreach efforts (Plescia, et al. 2008). Efforts to effectively reach all these individuals and persuading them to change their negative health behaviors have largely been unsuccessful due to a number of barriers including unpredictable attendance, difficulty estimating the effort needed to make a change, etc. Moreover, the growing numbers of ethnic minority women has made it difficult for WOHCDC or any one organization to fully meet the array of needs of this underserved population.

Elements of successful disease-prevention initiatives with the general population have included frequent contacts, and continuous care to promote maintenance over the long-term. Yet, such strategies are expensive, and may be impracticable to implement within the confines of limited resources: a scenario typical of most harm reduction agencies located in socioeconomically disadvantaged neighborhoods (Romero-Daza, et al. 1999). Based on evidence for best practices in promoting long-lasting change, the intervention described in this application utilizes core behavioral principles and strategies that aim to achieve lasting dietary and lifestyle modifications in this underserved population.

Participants

For the pilot testing of the current project, a group of 10 clients with the following eligibility criteria were selected from WOHCDC: a) English-speaking African American women; b) positive for HIV serostatus (documented by the facility staff through medical records, or demonstration of prescriptions, medications, medical appointments); c) used an illicit drug and/or alcohol in the last 90 days; d) between ages 21 – 55 years; e) have an additional chronic disease such as diabetes, hypertension or heart disease; and f) be willing to participate in a weekly 2 ½ hour group educational session for seven consecutive weeks.

Participants were recruited through a flyer posted at the facility. Interested and willing participants were asked to contact their case managers in order to be screened for the eligibility criteria. The technique of time-space sampling in street recruitment was also used to ensure an appropriate balance of individuals with differing degrees of services exposure; procedures used in HIV risk-reduction research and which we have successfully used in the past with this

population (Oransky, et al. 2009). During the initial contact, the facility’s trained staff asked participants to complete a brief demographic questionnaire to record the participant’s age, income, living situation, and medical history. Participants were also asked to complete a pre-test evaluation questionnaire to assess their knowledge and level of confidence in their ability to manage the complications associated with having multiple illnesses. Prior to administration of the questionnaires, informed consent was obtained. The facility staff was available to read the informed consent and the questionnaire items to those participants who may have had a difficult time filling them out on their own.

RESULTS

Project THANKS was conducted in seven (7) 2.5-hour group weekly sessions. Each session was designed to accomplish a specific goal and set of learning objectives. An outline of these sessions and their objectives is provided in Table 1.

Table 1. Implementation Plan

Session	Goals and Objectives
1. Needs Assessment	Assess participant needs, knowledge, attitudes, and beliefs, and barriers and experiences.
2. Personalized Goal Setting	Identify, prioritize, and take the necessary steps needed to achieve the program’s common goal of leading a healthy lifestyle, and staying on track.
3. Stress Management	Learn how to relax, and get enough exercise and sleep through a demonstration of basic exercise and relaxation techniques.
4. Nutritional Recovery	Learn skills needed to prepare healthy foods that adhere to nutritional guidelines for drug users faced with the dual diagnosis of HIV and another chronic illness such as diabetes, hypertension or heart disease.
5. Healthy Relationships	Learn to communicate better and ask for social support from partners, friends or family members.
6. Healthcare Participation	Learn to be a positive participant, understand the consequences of non-adherence to medication regimes, enhance knowledge about one’s health conditions, and to have the courage to take responsibility for one’s own health.
7. Media Advocacy	Learn to be proactive and use the media to publicize the need for improved educational programs and services that will help women like them have access to better health care.

Session One. Needs Assessment

The basic functions and activities associated with the treatment of substance abuse and HIV treatment within a harm reduction model, and implemented at community-based agencies across the country are essentially the same. However, the unique circumstances that affect a group of individuals living in a neighborhood requires special programmatic effort to help the group identify and access needed resources, and provide them with the necessary long-term support for their co-existence and optimum functioning in the community. With an increased focus on making sure that the limited funds are spent in the most efficient way possible, conducting a thorough needs assessment to assess the health problem, and its associated

determinants helps to ensure that an intervention can meet the targeted and unique needs of the at-risk population more effectively (Bartholomew, et al. 1998). In keeping with this approach, Project THANKS began with a focus group discussion to assess the specific needs of the HIV-positive black female clients of Well of Hope. Using the socio-ecological model as a guiding framework, the discussion attempted to capture how these women defined, conceptualized, and interpreted their overall health status in the context of having a chronic illness in addition to HIV, and the relationship of these perceptions to seeking and receiving appropriate health care in their community. Several major themes emerged upon analysis of the focus group transcript, which are detailed in a process evaluation manuscript currently under preparation. However, in order to provide a context for the subsequent intervention sessions, a brief summary of these findings is provided in this section.

An overarching theme that emerged throughout the discussion highlighted the women's beliefs about their general sense of self, self-efficacy and confidence level in being able to improve their health condition. Living and 'dealing with HIV and all these other diseases', and not having the 'right knowledge, skills and tools' to prioritize and manage the multiple complications associated with the comorbidities appeared to be a notable point of stress and frustration for all. Nearly all of them acknowledged to feeling 'helpless' and 'powerless' to change their condition. A major sub-theme that emerged highlighted the general social climate in their community, the women's perceived needs within this context, and the influence of the social environment on their health behaviors. Statements made by the women revealed a great sense of social isolation, stigma, and marginalization. Nearly all of them acknowledged 'feeling alone' as a result of no or minimal contact with friends and family. They believed that 'an opportunity to interact and socialize more with 'other people like us in recovery' was important in ameliorating the feeling of 'being depressed and lonely,' possibly even 'reducing stress,' thereby providing reinforcement and 'to feel encouraged to eat better and take better care of yourself.'

Another important theme that emerged throughout the discussions was related to their overall experience with seeking health care. A variety of obstacles seemed to 'get in their way' of 'keeping doctor's appointments regularly', including the fear of pain from having to endure medical procedures. Having caring and knowledgeable medical staff that tended to their needs was described as key to encouraging them to 'feel more safe' but regrettably lacking. During the course of the discussions, it became evident that the participants' beliefs about what they should or should not eat were very much anchored in their own personal definitions of good health. Eating sufficient amounts of foods with high energy content, eating balanced meals, and 'staying on top' of medical issues were all described as being essential to maintaining optimum health. Within this theme, there was an underlying tone of sadness and a yearning to 'look healthy' and to 'not look like an HIV-positive person that may be dying.' Issues related to their need for nutrition education were also highlighted. Most reported that while they had a 'general idea' on how to stay healthy, they lacked the knowledge to help them improve a specific medical condition. Having access to culturally relevant information that would help them overcome the obstacles they currently face in dealing with their multiple diagnoses, diseases, and combating the stigma associated with having HIV was deemed critical in their ability to have 'better control' over their health.

The intervention components were subsequently developed keeping these emergent themes in mind. Our primary objective was to develop a curriculum consisting of components

emphasizing that despite limited resources and inequity in health care access, adopting healthy lifestyle behaviors to prevent chronic disease risks, in addition to managing substance abuse and HIV-related health complications, is critical for overall wellness.

Session Two. Personalized Goal Setting

This session was developed with the aim of encouraging our participants to set realistic goals for themselves, and therefore, be effective agents of change in their own health care. The goal was to increase their motivation to take charge and make their health a priority. The beneficial effects of setting goals in nutrition education and maintenance interventions are well established. The technique of setting a specific goal has been shown to lead to measurable positive health outcomes, especially among individuals faced with challenging and difficult life circumstances (Cullen, et al. 2001). The activities in this session focused on first helping the women identify and understand the source of their feelings of helplessness, the consequences of these feelings (lack of motivation), and finally, the importance of regaining a sense of control over their life despite all of the health issues they may be dealing with. The message that helplessness is a learned phenomenon, and that it reduces the motivation to change was illustrated through a series of examples. The message that changing one's behavior (eating a balanced diet, exercising, and regularly monitoring blood glucose and blood pressure readings, watching out for heart attack symptoms) can influence the outcome (better control of diabetes, blood pressure and heart disease risks) was reinforced throughout the session. The reasons for why they should make a change to their lifestyle (compromises immune systems, help protect others, and prevent reinfection), the specific steps they should take to make these changes (gain more knowledge on their health conditions, be an active participant in their health care, abstain from drugs, and reduce risky behaviors), and the urgency of making these changes for improved health were all emphasized.

Through role-playing and case-scenarios that were relevant to the women's own life experiences, they were encouraged to identify the specific situations in which they felt particularly helpless, and the various ways in which they could motivate themselves to conquer these feelings. Mini-group sessions were convened during this session wherein they were encouraged to come up with strategies together that they felt would help them cope with the difficult situations they encountered in their daily lives. These group sessions were incorporated to help them understand the importance of sharing their struggles in a shared group setting, to develop social bonds with others, and to hold one another accountable for change. Through a variety of hands-on games and activities, they learned to identify a personal goal towards living a healthy lifestyle, and then list, prioritize, schedule, and take the necessary action steps to achieve this goal. At the end of the session, the facilitator encouraged group members to continue to review and schedule a time for the next set of action steps that they would need to complete in order to achieve their goal.

Session Three. Stress Management

Compared to men, low-income African American women have reported greater levels of physiological and psychological stress as they are confronted with "triple oppression associated with discriminations based on race, sex, and class" (Bova, et al. 2008; Sherman, et al. 2006; Braxton, et al. 2007; Williams & Williams-Morris, 2000; Hooks, 1993). This in turn, resulted in several exaggerated and negative coping mechanisms, including the tendency to engage in high-risk behaviors, and the reluctance to seek help and treatment (Murry, et al. 2003). This session began with asking the women to define the word 'stress', and to discuss the various situations

that contributed to stress in their daily lives. They were encouraged to specifically talk about the ways in which having a comorbid chronic disease condition in addition to substance abuse and HIV leads to feelings of being overwhelmed and stressed. Handouts were distributed illustrating the negative influences of stress on their health including how it increases chances for infection, impairs their concentration and decision making, increases risk of high blood pressure and heart disease, leaves them feeling rundown, exhausted and demoralized, leads to depression and anxiety, interferes with digestion and absorption, and disrupts their sleep.

During the later part of the session, the women were asked to get together in smaller groups and reflect and share with one another the list of physical, emotional, and family/social signs and symptoms of stress they typically experience. A theme that was repeated throughout this session was to have them redefine the stressor, and to distinguish between healthy and unhealthy stress coping mechanisms. The importance of taking control of their stressors by learning how to relax, and getting enough exercise and sleep was emphasized through a demonstration of basic exercise and relaxation techniques such as stretching, visual imagery, progressive muscle relaxation, deep breathing, and positive affirmations.

Session Four. Nutritional Recovery

A lack of basic culinary skills required to prepare meals has been shown to be a significant barrier to consuming nutritious foods among members of this population; especially those that are homeless and may consequently lack basic kitchen amenities (Mahadevan & Fisher, 2010). Moreover, the synergistic influences of substance abuse and HIV, along with a multitude of contextual factors that are unique to the lives of low-income African American women, may impact their food behaviors to a significantly greater extent, ultimately leading to widespread nutritional abnormalities, and compromising their responsivity to treatment (Miguez, et al. 2003). The activities in this session were therefore focused on providing women with the needed skills to prepare and consume healthy foods that specifically adhered to nutritional guidelines for drug users faced with the dual diagnosis of HIV and other chronic illness such as diabetes, hypertension or heart disease. A variety of presentations and hands-on activities and tools such as the food guide pyramid, MyPlate, and the Dietary Guidelines for Americans were used to demonstrate the principles of healthy eating, and other ways to manage their symptoms through good nutrition.

The importance of choosing a variety of foods from the different food groups, reducing salt and sugar intakes, reducing consumption of sweetened beverages, incorporating more fruits and vegetables into their daily diets, and adhering to reasonable portion size guidelines was demonstrated with the help of food models and models depicting various sized silverware. Participants were also given newsletters and brochures with simple illustrations that emphasized how to avoid junk and fried foods and choose healthier alternatives especially at fast food restaurants and convenience stores. The discussion component was complemented by a cooking demonstration consisting of simple techniques to prepare healthier versions of traditional African American recipes such as baked chicken, collard greens cooked in vegetable broth, brown rice and vegetable pilaf, low fat corn bread, and mixed fruit salad with low fat whipped cream. All the recipes contained simple ingredients, and required only six or fewer ingredients that were easily available in their neighborhoods. Colorful, half-page recipe handouts consisting of these recipes, and other tips and strategies to prepare and eat healthy snacks were provided at the end of the session to encourage them to make the recipes at home on their own, and share them with their family members. For some recipes in these pamphlets, only a can opener, bowl, and mixing

spoon are needed to emphasize that they did not need to heat up a stove or oven, although some recipes may require a microwave, or toaster. The intention of this session was to have them try different foods and to teach them skills needed to easily choose, prepare, and eat healthy foods on their own.

Session Five. Healthy Socialization

Researchers have long speculated that supportive social relationships, strong family ties, an extended family system, religious involvement and participation, and cultural pride, may mitigate some of the negative effects of exposure to social and economic adversity, and positively impact treatment effectiveness, especially among HIV-positive individuals (Moore, et al. 2006). For African American women in particular, who have historically faced harsh social and economic conditions, extended family, and a more active involvement and participation in the community may help provide supportive social relationships, tangible economic resources, comfort in times of trouble, and motivation for engaging in healthy behaviors (Chatters, et al. 2002). This session was designed to help the participants understand that the type and extent of social relationships they have with their partners, friends or family members can play an important and crucial role in their recovery. The goal was to have them realize that an important part of recovering and pursuing a healthy lifestyle is to develop friendships and relationships with healthy boundaries. It was emphasized to them that ultimately these social networks can help them abstain from drugs, and take the necessary steps to improve their health (have someone to rely on for accompanying to doctor's visits, or simply be a shoulder to lean on during challenging times). Through open and honest discussions, role-play exercises, and case scenarios, they were encouraged to first reflect on, and identify those social relationships in their current or past lives that may be unhealthy and the activities possibly involved in these relationships (dealing and using drugs, stealing or engaging in other criminal activities, etc.). Then, by getting together in smaller groups, they were assigned the task of coming up with a list of communication strategies that they can use to rebuild these damaged relationships. Participants were also provided handouts with ideas for health-promoting leisure and work-related activities that they could engage in with their loved ones at home.

Session Six. Health Care Participation

Individuals living in impoverished neighborhoods may experience several environmental obstacles to maintaining optimum health, including inadequacies in access and utilization of information and health care resources for which they are typically eligible (Richards & Smith, 2006; Williams & Jackson, 2005). Experiences with poorly staffed or inadequate neighborhood health services and the lack of culturally relevant educational materials and advice, combined with a legacy of distrust in physicians born of historic abuses during slavery through the Tuskegee study and beyond can be significant barriers to accessing and complying with advice from health care providers (Whetten, et al. 2006). Health literacy is one of the most significant social influences that increase the disparities in health care access and participation between races (Osborn, et al. 2007). In a study among 204 HIV-positive patients recruited from clinics, the limited health literacy, particularly among African American patients further reduced their adherence to the HIV medication regimen. This session focused on teaching the women to be positive participants in their health care. The discussion sessions were designed with the goal of having the women understand that establishing and maintaining a positive, active and continuing relationship with their health care providers, and establishing medication adherence is critical to their recovery. Messages related to identifying and overcoming obstacles to adherence,

understanding the consequences of non-adherence to medication regimes, enhancing knowledge about their health conditions, and encouraging them to have the courage and take responsibility for their own health were all emphasized. Activities utilizing simple memory aids and techniques such as scheduling and setting reminder alerts for regular medical check-ups (blood glucose and blood pressure monitoring) and for improving medication adherence were incorporated into the session. The various ways in which they can pose important questions regarding their health, and communicate more effectively with members of their health care team were demonstrated through songs, role-play and case scenario exercises. Through these activities, the women learned to improve their skills for recognizing potentially dangerous symptoms early, and to keep their health symptoms in check.

Session Seven. Media Advocacy

Studies show that interventions with advocacy and issue-specific community outreach training components can play a significant role in empowering individuals to be key change agents in their own community. Giving impoverished HIV-positive ethnic minority women the tools to organize and educate each other, public officials, journalists, and the general public, on issues important to them, their families, and the communities in which they live, is an essential element to achieving the end of the cycle of poverty, high-risk behaviors, and disease transmission (Freimuth & Quinn, 2004). Using the American Public Health Association's Media Advocacy Manual as a guiding model (American Public Health Association, 2000), the activities in this session were designed to teach the women to be proactive and use the media to publicize the need for improved educational programs and services that will help individuals like them have access to better health care. In a series of simple steps, they learned to first develop an overall strategy for their cause, create a list of local media sources in their area, prepare a simple yet effective document showcasing their message clearly, write a letter to the editor of a newspaper or magazine or TV channel explaining their message, arrange a meeting with the particular media source or use other public forums and meetings to present their issue, and develop simple tips and tricks for following up with the source, and continue to advocate for their cause.

At the end of the last session, participants were encouraged to bring their family members and friends to a 'graduation party' event, where they celebrated their efforts by receiving graduation certificates, gifts, and other reinforcement materials to stay on track and follow through with the goal of living a healthy lifestyle.

DISCUSSION

A variety of formal outcome and process evaluation methods consisting of a combination of qualitative and quantitative techniques were used to test the effectiveness of the intervention. Data evaluating the program's effectiveness on increasing the participant's self efficacy, and her confidence level in being able to manage all the health conditions was collected using standardized questionnaires and scales. The Stanford Chronic Disease scale has been found to be a quick, valid, and reliable tool for identifying knowledge and skills for chronic disease management (Lorig, et al. 2001). Portions of the scale that were most relevant to the program components were selected to assess their self-efficacy across domains, including managing symptoms and obtaining help from their family and friends for emotional support or with their daily needs. Additionally, certain components of the SISTA and HRRP evaluation tools that has been pilot tested and proven to be effective in increasing HIV knowledge in African American women were included in the evaluation component. Specifically, questions that test the

participant's knowledge of condoms, HIV infection, and methods of transmitting HIV were used. These instruments were administered during the needs assessment phase as well as during the final session. The variability in the pre- and post-intervention data will be assessed using standard statistical tests including descriptive statistics such as frequencies, means, medians and inter-quartile ranges.

The overall feasibility of the implementation protocol was examined using qualitative methods. The program planners took extensive notes on the various administrative aspects of the program including the number of eligible individuals who initially agreed to participate in the project, rates of attrition, group attendance at each session, reasons for dropouts, reports of facilitator burden, and the facilitator's overall experience with the project. Using a semi-structured guide, a culminating focus group discussion was also conducted to gather information on the participants' overall experiences with the intervention, including satisfaction or concerns with various components of the intervention, and suggestions for future adaptations, etc. The emergent themes from this focus group will be compared with the themes from the focus group conducted during the needs assessment phase in order to understand any non-quantifiable factors that affect the women's participation, including stigma and discrimination, and the typical barriers and challenges faced by these women in accessing such services and support (Guba & Lincoln, 1985). A more detailed description of the afore-mentioned evaluation data, which is currently under analysis, will be reported in a subsequent manuscript.

CONCLUSION

Despite the evidence on the pivotal role of antiretroviral medications in prolonging the life of HIV-positive individuals, the incidence of chronic disease risks, along with a multitude of contextual factors that are unique to the lives of impoverished African American women, may continue to impact their health to a significantly greater extent. Drawing on available evidence from intervention science literature, we have proposed a dynamic care plan that places the life experiences of these women within a socio-ecological framework; one that considers the various ways in which cultural and street norms and preferences, historical marginalization and racism, disease severity, individual needs, disparities in the access of neighborhood resources, and psychological distress might intersect to affect their ability to prioritize and manage the multiple complications associated with HIV and related comorbidities. Components that focus on personal control and self-esteem form the cornerstone of the intervention. The goal is to help provide an avenue by which the women can regain control over their bodies, and achieve nutritional rehabilitation and overall good health (Zule, et al. 2002).

There are some limitations to this pilot study. Due to budgetary restrictions, the sample size was kept relatively small, and limited to participants from one urban area. The findings from the needs assessment and evaluation phases may be a reflection of the location where the data was collected. Therefore, we have insufficient information to fully examine representativeness of our sample to HIV-positive women in other urban neighborhoods. Additional research is needed to test the applicability of our intervention to other samples and a larger population. Nevertheless, despite the small sample size, this study is noteworthy because at present we know very little about how ethnic minority women dealing with HIV as well as another chronic condition manage their overall health. Our project represents an initial step in understanding an understudied population. Many of the issues discussed by the recipients of our intervention could be applicable to a large part of the HIV-positive community in other parts of the country.

Project THANKS hopes to make a broad impact on its participants and the community by achieving the following outcomes:

- 1) Build group trust and cohesion. By bringing the participants, their families, friends, program planners, program delivery staff, and the community together in a partnered enterprise, and by getting everyone to engage in a free dialogue with one another in a safe, shared and supportive space, the program aims to expand the women's social networks, thereby increasing their self-efficacy and minimizing feelings of marginalization and social isolation.
- 2) Advocate for change. By teaching women how to advocate for their issues to local media sources and politicians, the program allows them to become empowered, and take responsibility for their own health. But also, the advocacy component gives women the unique opportunity to lend their voice to establishing more effective public health policies that reduce health disparities and promote health in their community.
- 3) Establish goals for change. By encouraging the participants to set personal goals, and devise action-steps or strategies that are more suited to their unique contextual needs, the program allows for tailoring the educational messages to their realities, thus increasing the likelihood of sustainable and lasting changes.
- 4) Self-monitor and evaluate. Using continuous monitoring and feedback procedures, and based on the proven strategy of "reflect-speak-act", the program encourages participants to continuously monitor and reflect on their own progress so that they are able to self-assess the barriers to implementation, and adapt the strategies accordingly.

Should these outcomes be met, it is our intention to sustain and build upon the community partnerships created for this project through implementation of the intervention at harm reduction agencies across the state and nationally, by creating new models of service, and by providing "on-site" trainings and workshops collaboratively with the agency staff. Expanding the application of the socio-ecological framework to other programs serving marginalized and underserved populations can play a critical role in promoting health among them. The long-term goal of Project THANKS is to help experts benefit from community knowledge and experience in ways that can be used in their future work with the target population.

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