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Barriers and facilitators to engagement in lifestyle interventions among individuals with HIV

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Since the mid 1990s, the availability of antiretroviral therapy (ART) has prolonged the survival of individuals living with HIV and the disease can be managed as a chronic illness. However, cardiovascular disease (CVD) contributes to nearly 10% of deaths among HIV-infected individuals (Sabin et al., 2008). People living with HIV infection (PLWH), especially those on ART, appear to have increased rates of dyslipidemia (Triant, Lee, Hadigan, & Grinspoon, 2007), insulin resistance (Tebas, 2008), and fat abnormalities (Grinspoon & Carr, 2005), all of which are direct or indirect cardiac risk factors. The increase in these complications may be related to the HIV infection itself and/or the use of certain antiretrovirals (Grinspoon & Carr, 2005).

Although studies have suggested HIV-associated complications such as wasting remain common (Mangili, Murman, Zampini, & Wanke, 2006), more recent studies have found PLWH to be increasingly overweight and obese (Mulligan et al., 2010). Overweight or obese status and fat redistribution confer increased risk for chronic conditions such as

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hypertension, CVD, and diabetes, potentially adding significantly to the disease burden, survival, and quality of life. In our previous cross sectional study of 123 HIV-infected patients, we found that 33% were overweight [body mass index (BMI) of 25–29.9 kg/m²] and 29% were obese (BMI ≥ 30 kg/m²). Of the 123 participants, 88.6% reported using ART, and approximately 5% reported that their physical activity was “vigorous” (activity that causes one to breathe harder) for a minimum of 10 minutes per session (Capili, Anastasi, & Ogedegbe, 2011).

As certain CVD risk factors can be prevented or modified through lifestyle changes, these data suggested that nutrition, weight management, and physical activity should be important components of HIV care to reduce medical comorbidities, mortality, and health care costs. The integration of nutrition interventions in HIV management such as following a heart-healthy diet and exercise program have been shown to reduce dyslipidemia in PLWH (Fields-Gardner & Campa, 2010). In an open label study of 230 HIV-infected patients, a low-fat diet was successful in reducing cholesterol levels by 10% and triglyceride levels by 23% after 6 months of therapy (Barrios et al., 2002). A cross sectional study has also shown a correlation between diets low in dietary fiber and insulin resistance in PLWH (Hadigan et al., 2001). However, in real life making changes to one’s diet and improving healthy habits are much more complex. We studied focus groups to identify the barriers and facilitators for PLWH in a large urban setting to improve our understanding of therapeutic lifestyle interventions for the HIV population.

The Health Belief Model (HBM; Rosenstock, Strecher, & Becker, 1994) and the Social Cognitive Theory (SCT; Bandura, 1994) guided our exploratory and descriptive study. According to the HBM, individuals take action if they perceive they are at risk for a health condition, perceive that the condition can have serious consequences, and available prevention/treatment options can reduce the risk or severity of the condition (Rosenstock et al., 1994). Individuals must also perceive that the barriers to taking an action are outweighed by the benefits. According to the SCT, knowledge and awareness of health risks may not be enough to promote behavior change (Bandura, 1994). For behavior change to occur, individuals must not only be given reasons to modify behavior, but also have behavioral capability, resources, and social supports to change as well as a strong belief in his or her efficacy to exercise personal control (Bandura, 1994). Our focus groups explored the personal and in-depth detail of expectations, perceptions, and beliefs related to a healthy lifestyle and behavior in patients infected with HIV. The findings in this paper summarize the recurring theme of barriers and facilitators to healthy behavior across all focus group participants.

Methods

A purposive sample of 123 participants were recruited to participate in 21 focus groups composed of 5 to 6 persons per group. Sample size was determined by data saturation from the group interviews. The focus groups took place on site at an academic medical center in New York City and received approval from the institutional review board of the university. Participants were recruited using flyers and brochures posted in HIV community-based organizations and health fairs specific to HIV care. Participants initiated inquiry about the

study and were telephone screened to determine preliminary eligibility. The eligibility for participation included: 18 years of age or older; HIV infected; a score of 24 or higher on the Mini Mental State examination; the ability to read, write, and speak in English; and agreement to share experiences in a group setting with audiotaping. Exclusion criteria included: history of CVD, defined as history of myocardial infarction; angina pectoris; stroke; transient ischemic attack; cardiovascular surgery; coronary artery stents; congestive heart failure; peripheral vascular disease; and thoracic or abdominal aortic aneurysm. The composition of the groups was segmented by gender and BMI, calculated as weight in kilograms divided by the square of height in meters. The composition and number of focus groups completed were as follows: (a) normal weight men (BMI, 18.5–24.9 kg/m²), 4 groups; (b) normal weight women (BMI, 18.5–24.9 kg/m²), 4 groups; (c) overweight men (BMI, 25.0–29.9 kg/m²), 4 groups; (d) overweight women (BMI, 25.0–29.9 kg/m²), 3 groups; (e) obese men (BMI, 30.0 kg/m²), 2 groups; and (f) obese women (BMI, 30.0 kg/m²), 4 groups. All study participants attended one intake session and a second session for their scheduled focus group. Participants received \$20 for completing their assigned focus group and each group lasted approximately 1.5 hours.

We used focus group methods described by Morgan and Krueger (1998), and questions were developed according to guidelines by Krueger (1998) in which sequencing of questions was designed to move from general to specific, focusing on key concepts of the study (See Table 1). General information about dietary preferences led to specific explorations of dietary habits, coping with nutritional needs, maintaining a healthy lifestyle, challenges, and helpful strategies. The purpose of sequencing study questions from general to specific was to allow the participants to get acquainted with the topic and to give each participant the opportunity to recollect personal opinions and experiences and to listen to others (Krueger, 1998). At the end of each focus group, the moderator gave a 2–3 minute oral summary of the key questions and ideas that emerged from the discussion. Participants were asked to comment on the adequacy and accuracy of the summary (Krueger, 1998). A member of the research team served as the moderator while two members of the team took notes for notable quotes and nonverbal observations such as silent agreement and body language, which may not be captured on electronic recording devices (Krueger, 1998).

After the completion of each focus group, a debriefing session took place so that the first impressions of the group discussion were not forgotten and provided the opportunity for the team to compare what each team member heard. If the team members disagreed as to what was heard, the team was required to listen to the audiotape. A systematic coding scheme based on the framework from the HBM and the SCT was developed after completion of the first focus group.

Each focus group was audiotaped and professionally transcribed verbatim. Transcripts were entered into NVIVO[®] software to organize the text-based data for qualitative analysis. Preliminary impressions of each transcript were reviewed and discussed by three team members; comparisons of observation notes from each debriefing session were also reviewed for congruence. Emergent themes were identified and coded iteratively, and agreement was reached by consensus with each transcript reviewed a minimum of three times.

Results

Our sample was 60% male and 40% female, with a mean age of 48 years ($SD \pm 7.3$; See Table 2). We organized responses into two broad areas: barriers and facilitators to healthy behavior. The area of barriers was further subdivided into categories of socioeconomic status, cultural/psychosocial, environment, and social support. The area of facilitators was subdivided into categories of patient/provider communication, group support, physical activity, and motivation or positive attitude.

Barriers to Healthy Behaviors

Socioeconomic/financial—Health outcomes and quality of life for PLWH are influenced by socioeconomic status. Low-income PLWH have higher mortality rates than HIV-infected people who have higher incomes and more education (Cunningham et al., 2005). PLWH with lower incomes tend to eat more fast foods, drink more fruit juices, and have diets of lower nutrient density (Hendricks, Mwamburi, Newby, & Wanke, 2008). In many low-income neighborhoods, there are an abundance of fast-food outlets, liquor, and convenience stores to buy cigarettes, but few large grocery stores with a wide selection of fresh foods. Persons in disadvantaged areas with less access to healthier foods also consume fewer fruits and vegetables and have higher body weight (Inagami, Cohen, Finch, & Asch, 2006).

Many of the participants in our study cited financial cost as a barrier to making healthy choices related to food and nutrition. One respondent stated, “When you eat clearly, cleanly, you feel light ... but our budgets don’t afford us that luxury. If I could, I would eat totally differently but it would cost me so much.” They reported being on limited budgets and how expensive fresh quality produce was in their neighborhoods. Participants often mentioned the limitations of being on the Supplemental Nutrition Assistance Program (formerly known as Food Stamps): “They opened up these nice beautiful stores and all ready gorgeous fruit line the whole sidewalk. I went in there and they don’t take food stamps.”

For those with limited resources, many try to stretch their budgets by buying cheap, energy dense foods (refined grains, added sugars, and fats) that are filling but are nutrient poor (Drewnowski & Darmon 2005). In addition, some of the participants had attended healthy eating education programs but cited the unavailability or impractical nature of the information offered. One man summarized his experiences by saying:

Sometimes I go to a nutritionist cooking class. But this food comes from - for the recipe, they give us a recipe from Fresh Direct or either the organic supermarket. If you’re living on a budget or on disability and you’re getting food stamps, you cannot buy – you can’t afford to buy the stuff because food stamps doesn’t give you that allowance.

Cultural/psychosocial—In addition to socioeconomic factors, health-related beliefs and attitudes usually are established early in life and are determined by cultural and psychosocial factors (Hochbaum, 1981). For example, cultural variation exists in the perception of weight as a health risk. In many non-Western traditional societies and ethnic groups living in the

United States, body fat or plumpness is seen as a standard of beauty, an indicator of fertility, prosperity, and economic success (Brown & Konner, 1987). As one woman stated, “All the women in my family are big, so I ain’t trying to lose no weight ... because you’re big or you’re too small, that don’t mean that you’re not beautiful.” Further, cultural notions of food consumption and taste preferences are often shaped in early childhood and may impact dietary habits and choices as adults (Nestle et al., 1998). One respondent stated, “I’m coming from a generation of using salt ... So I’m so used to grabbing the salt. Because listen, where we eat, you’ve got to put salt and pepper on.” As another participant explained, “I’m HIV positive but I feel I’m in good health. I know it’s hard when you grow up eating pork chops and going to McDonald’s, Burger King, and certain places, you still get that taste.”

For many individuals living long term with HIV, the visual markers of the early years of the HIV epidemic were weight loss and wasting syndrome. PLWH may try to gain weight to avoid the social stigma associated with HIV. Appearance concerns are common in PLWH as the illness and/or treatment may affect body changes such as increased fat in the belly, neck, shoulders, breasts, and face (Blashill, Gordon, & Safren, 2012). One participant reported, “I’m not too big but I had like a little pouch. And when I looked at the mirror, I didn’t like what I was seeing at one point and I got too heavy.”

Environment—Many of the participants expressed the importance of having a stable environment, related to their housing or living arrangements; as one explained, “It takes a stable lifestyle to do those things [focusing on nutrition].” Unstable situations may include rotating housing among family and friends, living in single-room occupancies/welfare hotels, or recovery or transition housing. Many of the participants expressed the difficulty of maintaining self-care regimens in their environments; as one person stated, “Sticking to a diet has been hard for me. Staying on a daily regimen of exercise has been hard, and I’ve given up on both of those things.” Another participant said, “Where I live, what’s around me, it’s just not healthy....people smoke, people drink. I only moved there because I was in the shelter. Once I move, I change my environment, my lifestyle will change.”

Social support—The social environment includes influences and interactions with family, friends, peers, and others in the community and may impact healthy behavior and food choices through role modeling, social support, and social norms (Abrams, 1991). The association between social support and HIV health outcomes is inconclusive, but social support may be a predictor of HIV disease progression (Ashton et al., 2005). One female participant described the burden of being single, “A good majority of us live by ourselves or live in those single rooms and a lot of us never learned to cook. Those that have families, they know because they have kids and kids need to eat balanced meals so you cook a balanced meal. Behavior change is more likely to be sustained when a person’s environment is simultaneously changed in a manner that supports the behavior change (Abrams, 1991).

Facilitators to Healthy Behavior

Patient/provider communication—The quality of the patient-provider relationship and communication has been shown to improve PLWH adherence to therapy (Johnson et al.,

2006). The effects of patient provider communication have also been reported in health-related behavior for patients with CVD where counseling, frequent provider contact, and feedback have been shown to increase adherence to dietary change (Artinian et al., 2010). One participant summarized it by saying, “I want my doctor to explain it to me. Tell me what I can eat, can’t eat, and tell me what I’m looking forward to if I don’t eat the right foods.” Many of the participants commented on the importance of these relationships. One person recounted his experience with his providers: “The bond I have with my nutritionist and primary doctor, we talk a lot, especially my nutritionist. We’re very close. That helped me a great deal in staying focused.” Another individual described his experience:

I’m the type of person who wouldn’t read labels. I just eat whatever, but I’m saying talking to my nutritionist, he explained to me eat certain things, more vegetables. He used to talk to me about my diet because my cholesterol was a little high. So from that, I just started to be aware of what I was eating.

However, the quality of the interactions from interventionists ranged from being very involved “We write a menu for me that week, and see if I could follow that.” to ambivalence, “My experience is the only time you see a nutritionist is when you is losing weight or have lost weight or you’re gaining too much weight. But other than that we don’t see no nutritionist.”

Group support—Social support from family and friends has been associated with a beneficial effect on several behaviors (physical activity, medication compliance, diet) that directly or indirectly affect the risk of cardiovascular disease (Ford, Ahluwalia, & Galuska, 2000). Often, another family member’s illness precipitated change in dietary habits as one man reported, “My mother-in-law was a diabetic and being that we used to eat with her every Sunday, so I stopped eating fried foods because she had ... she didn’t cook fried foods.” Many participants expressed the support of family and friends to staying healthy such as: “My daughter doesn’t allow fried foods in my house at all. She told me she was going to buy me a wok to learn to stir fry.”

In addition, many participants expressed the desire for and benefit of organized support groups and activities. One individual reported, “I go to support groups, where I benefit due to the simple fact of everybody else experiences it and can be motivated by something you said.” Another participant said he would like, “A nutrition support group... where we sit down and have lunch together and we talk about nutrition and stuff, what the ingredients are.” Some participants expressed preferences for one-on-one counseling and buddy systems in addition to group support:

I would start off with a personal trainer, one-on-one, so the person would get to know this person and what their special needs are. Once they develop that and they see that the person has committed themselves, then I would move them on to a buddy-buddy system. And then after you’re doing well there, then I would send them on to the group. Then everybody incorporated into one because then one can continue to encourage the other.

Others mentioned the benefit of individual programs tailored for a specific interest such as incorporating physical activity into the daily routine or how to cook healthy with canned

foods. One participant stated, “Some people’s diets are different than others. You have to design a diet that’s going to fit that particular person.” Many of the participants echoed the need for interactive, hands-on learning:

Take them shopping so they learn how to buy healthy foods. You take them to a pantry and then you give them a cooking class on stuff that they’re getting in the pantry ... they get a whole lot of canned stuff but a lot of people don’t know that you can get all of that kind of stuff [proteins, fiber] in cans ...teach them how to cook stuff that’s in cans.

Physical activity—Many of the participants understood and recognized that physical activity was an important area of focus along with diet to staying healthy: “You can’t do one without the other; they’re hand in hand.” Financial cost was cited as an inhibitory factor in undertaking certain types of physical activity; as one woman explained, “I would like to go to a gym but I don’t have the money for it.” But a majority of the participants said that walking, as a form of physical activity, was practical, accessible, easy, and cost free. One participant said, “I can’t do jumping jacks and all that stuff. I live on a hill and I try to walk up this hill to go to the train station or wherever.” For others, physical activity with a partner or group was considered a motivating factor. One woman summarized by saying:

I tried going to the gym in the parks departments and it’s terrible. The crowd that goes in there, I just can’t deal with it. So, it would be better if you taught me how to do it. I would love a buddy system with somebody, that really, really is dedicated to losing weight and wants to better themselves.

Motivation/positive attitude—Self-motivational concern, desire, and intention play a large role in eliciting behavior change and adherence to interventions. During our focus group interviews, many participants expressed the importance of maintaining a positive attitude; as one individual explained, “Positive attitude ... gives you that motivation to encourage you more on exercising and doing better things for yourself.” Augmenting a patient’s motivation or patient centered counseling has been used to modify a variety of health care behaviors, including HIV risk reduction in low-income women (Carey et al., 2000) and dietary change such as increasing fruit and vegetable consumption (Resnicow et al., 2001). In addition, supermarket shoppers with positive attitudes toward healthy eating have demonstrated equally higher-quality diets with more daily servings of fruits and vegetables even if they shopped at low-, medium-, or high-cost supermarkets, independent of socioeconomic status and other covariates (Aggarwal, Monsivais, Cook, & Drewnowski, 2013).

Discussion

The reported experiences of the participants in our focus groups identified a variety of factors that PLWH faced in meeting the challenges of living a healthy lifestyle, regardless of gender or BMI. While diet and physical activity were acknowledged to be important components of a healthy lifestyle, socioeconomic or financial reasons were primary barriers to healthy behavior and social support was seen as a primary facilitator. The rich information reported here illustrates the desire and need for lifestyle interventions that

address limited financial resources and the use of social resources with communities and/or families. For lifestyle interventions to be successful in the long term, recommendations must include more than just telling a patient a list of foods to eat and to avoid. Advising people to buy only fresh fruits and vegetables is restrictive for individuals with lower incomes because available frozen or canned forms can have advantages in terms of price, seasonal availability, and storage. Processed vegetables, including soups and juices, can contribute to the quality and the affordability of the diet (Drewnowski, 2013). By exploring these perceived barriers, we can challenge researchers and health providers to adapt lifestyle interventions that accommodate the dietary habits, nutritional needs, and resources of certain populations.

Many individuals ate away from home and needed knowledge to determine healthy replacement choices at fast food outlets, vending machines, sports arenas, and cafeterias. Participants reported their willingness to learn about healthy eating choices and portion sizes, to try new cooking techniques and foods, and were very enthusiastic about sharing knowledge amongst each other. Understanding positive facilitators from the patient's perspective provides the basis for patient-centered counseling approaches to motivate people to change behaviors.

As evidence grows that PLWH face metabolic abnormalities and obesity, the increased risk of CVD is a major consideration for the care of these patients. For health care providers and researchers, preventable and modifiable CVD risk factors should be an important component of care. Currently, there are limited data on modifications of diet and lifestyle for PLWH. Future research on the feasibility and efficacy of lifestyle intervention programs to reduce CVD risk is warranted on this important – and modifiable – health concern for PLWH

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Table 1**Key Structured Interview Questions**

1	What does good health mean to you? (perceived benefit)
2	When someone says “Heart Healthy Lifestyle” how do you interpret this? (perceived awareness)
3	On the piece of paper provided, jot down health conditions or health problems which can cause or lead to heart disease. (perceived awareness)
4	Think back over the past several years. Have you made any changes in your life that could affect your health? (i.e., in what you eat, smoking habits, or exercise habits? Tell us about them. (cues for change)
5	What were helpful for you to make the changes? (social support)
6	What helped you or would have helped you the most in making the change? (self-efficacy)
7	Tell us about the things you tried to do but discontinued; the changes you tried to make but were not able to follow. (perceived barriers)
8	Suppose you were told by your doctor that your cholesterol level or blood pressure or sugar level was high. What would you want to know, or what kind of information would you like to get? (perceived threat, susceptibility)
9	There are lots of different ways you could get the types of information we have just talked about. How would you like to get that information? (social support)
10	We realize that it’s hard to stay interested to learn and to follow health information/advice about following a heart healthy lifestyle, but what would keep you interested?

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Table 2Summary of Demographic and Clinical Data ($N = 123$)

Characteristic	Results
Age, years $\pm$ SD	48 $\pm$ 7.3
Gender, male, n (%)	74 (60.2%)
Race/Ethnicity, n (%)	
Black	88 (71.0%)
White	3 (2.4%)
Hispanic	20 (16.1%)
Native American	2 (1.6%)
Other	10 (8.1%)
Cigarette smoker, n (%)	82 (66.6%)
Number years smoked, years $\pm$ SD	15.4 $\pm$ 14.3
Duration of HIV Diagnosis, years $\pm$ SD	15.3 $\pm$ 5.9
Waist circumference, cm $\pm$ SD	
Male	95.8 $\pm$ 12.2
Female	99.3 $\pm$ 13.2
Body Mass Index, kg/m ² $\pm$ SD	
Male	26.0 $\pm$ 4.4
Female	29.0 $\pm$ 5.9

Note. SD = standard deviation.