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Publication Date

2017-10-01

DOI

10.1016/j.apnr.2017.07.002

Peer reviewed

A multinational qualitative investigation of the perspectives and drivers of exercise and dietary behaviors in people living with HIV

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Abstract

Globally, people living with HIV (PLWH) are at remarkably high risk for developing chronic comorbidities. While exercise and healthy eating reduce and mitigate chronic comorbidities, PLWH like many others, often fail to engage in recommended levels. We qualitatively examined the perspectives and contextual drivers of diet and exercise reported by PLWH and their health care providers. Two hundred and six participants across eight sites in the United States, Puerto Rico and Botswana described one overarching theme, Arranging Priorities, and four subthemes Defining Health, Perceived Importance of Diet and Exercise, Competing Needs, and Provider Influence. People living with HIV and their health care providers recognize the importance of eating a healthy diet and engaging in regular exercise. Yet there are HIV-specific factors limiting these behaviors that should be addressed. Health care providers have an important, and often underutilized opportunity to support PLWH to make improvements to their exercise and diet behavior.

Keywords: HIV; Cardiovascular diseases; Exercise; Diet; Qualitative research

Abbreviations

ART, Antiretroviral therapy; CVD, Cardiovascular disease; PLWH, People living with HIV/AIDS; PI, Principal Investigator

1. Introduction

Antiretroviral therapy (ART) has led to increased life-expectancy of people living with HIV (PLWH), and today, more than 25% of PLWH are now 55 years of age or older (Centers for Disease Control and Prevention [CDC], 2015). With this increased life expectancy, PLWH are facing new health challenges related to an increased risk of non-AIDS related conditions including cardiovascular disease (CVD), cancer, neurocognitive decline, and bone disease (Paisible et al., 2015, Sico et al., 2015, Tseng et al., 2012). The benefits of a healthy diet and exercise behaviors are well established nature, and include a reduction in the incidence of CVD events, type II diabetes, hypertension, and obesity (Dufour et al., 2013, Fletcher et al., 1996, Kokkinos and Myers, 2010, Lee et al., 2012, Smith et al., 2010; United States Department of Health and Human Services [DHHS], 2008). PLWH may achieve these benefits and mitigate damage caused by long-term HIV infection, but little is known about specific factors that drive these self-management behaviors in this population. The purpose of this article is to present the results of a secondary analysis of physical activity and diet data collected in a large qualitative study that included PLWH, HIV providers, and other members of HIV healthcare teams.

Healthy diet and exercise are widely recommended strategies to achieve and maintain health, yet many PLWH do not engage in recommended levels of physical activity and are at high risk for nutritional deficits. The National Institutes of Health Office of AIDS Research has placed high priority on the development of strategies to prevent comorbidities and promote health in PLWH. There is an urgent need for interventions tailored to PLWH that will enable us to achieve these goals and provide PLWH with the tools to achieve health in their everyday lives. Yet, research has demonstrated the need for an in-depth understanding of the contextual drivers of exercise and dietary behaviors in specific populations to develop effective interventions. Such contextual drivers include factors that are personal (e.g. disease-specific, demographic), related to the physical environments in which one lives and works, account for social networks and social capital or are structural (e.g. food security); Larson and Story, 2009, Richard et al., 2011, van der Horst et al., 2007). Yet to date, no one has described the contextual drivers influencing exercise and dietary behaviors in PLWH.

PLWH are disproportionately affected by a number of biopsychosocial challenges that may impact their ability (or perceived ability) to engage in healthy exercise and diet behaviors. These challenges include a life-long disease and treatment trajectory with associated symptoms, social isolation, low social capital, chronic stress and stigma, depression and anxiety, higher rates of smoking and alcohol use, and polypharmacy (Do et al., 2014, Kaufman et al., 2014, Latkin et al., 2007, Latkin et al., 2013, Patil et al., 2014, So-Armah and Freiberg, 2014). To better understand contextual factors that impact diet and exercise behaviors in PLWH and to create effective interventions, we need an in-depth understanding of how PLWH perceive diet and exercise in their lives. Qualitative methods allow researchers to gain detailed insight from target populations, particularly when a phenomenon is vague or poorly understood. We conducted a secondary analysis of data collected in a larger qualitative study on health literacy in PLWH, to achieve the following aims: (1) to describe how PLWH view diet and exercise in the context of their lives and (2)

to identify contextual drivers related to diet and exercise in adults living with HIV from the perspective of PLWH and their health care providers.

2. Methods

2.1. The parent study

The parent study was conducted by an international network of HIV/AIDS nurse researchers (Holzemer, 2007) with an aim of gaining an in-depth understanding of health literacy among PLWH (Dawson-Rose, et al., 2016). Study participants included adults living with HIV (n = 135), healthcare providers including physicians and nurse practitioners (n = 32), and healthcare team members including nurses, social workers, and physician assistants (n = 39). Participants signed up for the study by responding to flyers posted within HIV care and advocacy organizations, and were included if they (1) were 18 years of age or older, (2) were able to provide informed consent, (3) were fluent in their local language, (4) self-reported an HIV-positive serostatus if participating as a person living with HIV. Participants were screened using the Mini-Mental State Exam (Folstein, Folstein, & McHugh, 1975) and were excluded for scores of 20 or less due to moderate-to-severe cognitive impairment (n = 3). Nurse researchers experienced in qualitative HIV research conducted 28 focus groups in which PLWH, providers, and healthcare team members were asked questions related to ways in which PLWH gained knowledge about HIV (see Table 1). To ensure consistency in data collection across sites, all focus group facilitators completed the same 1.5-day focus group training. Participants were asked additional questions to gain knowledge about their understanding of HIV and the need for treatment, with a goal of gaining understanding of HIV-related health literacy. All data were collected in 2013–2014. Focus group data were audio-recorded, translated (where necessary), and transcribed for analysis. The research team analyzed each transcript to create a codebook, with 15% of transcripts verified at 90% intercoder reliability (Dawson-Rose, et al., 2017), an expert in HIV qualitative research then reviewed and coded each transcript for consistency. The research team then used content analysis to reduce the data into major themes that came from the focus group discussions for further analysis. Diet and exercise behaviors were commonly discussed across focus groups, and were coded within the major themes of “Health Behaviors” and “Taking Ownership of One's Health”. Focus groups from which these codes were derived were used the dataset for this analysis.

2.2. The present study: Data analysis

The research team reviewed focus group transcripts to identify and isolate content related to diet and exercise. The researchers identified 198 sections of text (e.g. quotes, conversations, paragraphs) across focus groups, and included participants from all three strata. We used conventional qualitative content analysis (Hsieh & Shannon, 2005) to guide our analysis. Two research team members trained in qualitative analysis independently reviewed the transcripts for preliminary codes related to diet and exercise, noting key words and concepts discussed by participants. The researchers then collaborated to discuss their preliminary codes, which they organized into meaningful categories (e.g. provider recommendations for exercise and diet; favorable/unfavorable perceptions of diet and exercise by PLWH) for further analysis. After further collaborative discussions, the researchers

refined the initial categories and merged similar categories to develop themes that found consistently across all or many transcripts. Two research team members conducted a third analysis of data and reached consensus that categorical and thematic saturation had been reached. Finally, all investigators involved in the parent study and reached unanimous agreement that their findings accurately represented the data, and that exemplars accurately represented each theme.

3. Results

3.1. Themes

We identified one overarching theme, Arranging Priorities, and four specific themes, Defining Health, Perceived Importance, Competing Needs, and Provider Influence. Table 2 details the four themes and in the following paragraphs we present the theme and provide quotations as case exemplars.

3.2. Arranging priorities

Participants commonly discussed the role of self-management behaviors to maintain health, including diet and exercise. Participants were of diverse backgrounds, geographic locations, HIV disease stage, and socioeconomic status, and their perceptions of diet and exercise were equally diverse. PLWH, providers, and healthcare team members shared agreement that healthy diet and exercise behaviors were beneficial to maintaining health. Differences in their experiences and perceptions were often linked to the level of priority these self-management behaviors took in their lives (PLWH) and the lives of their patients (providers, healthcare team members). For example, some PLWH shared their belief that a healthy diet and exercise were of equal importance to their health as pharmacological therapies for HIV, while others believed that the health behavior that mattered the most in their lives was medication adherence to maintain an undetectable viral load. Among providers, there was a desire for their patients to adopt healthy self-management behaviors but also a realization that amidst the challenges they face, expectations and treatment goals had to be realistic and attainable. In this way, it became clear that a common thread that connected discussions of diet and exercise was the arrangement of priorities that best suited their lives (PLWH) and guided supportive interactions with their patients (providers, healthcare team members). Thus, arranging priorities was an overarching theme in our analysis.

3.3. Defining health

A key finding among PLWH centered on the different ways that they define health, and how their own definitions influenced their perspectives on diet and exercise. Some participants defined health as being reflected by what they were told by their providers. Often, these definitions were shaped through discussions of lab values (particularly those related to HIV). One participant expressed that she did not concern herself with healthy eating or exercise because her provider told her she was in good health:

“And so every time I go see my doctor, he says ‘Whatever you're doing, just keep doing it,’... He's like ‘You are still in good shape after (being diagnosed with HIV in)

1997,' so I don't follow any of this (diet and exercise recommendations). I just tell him to let me know when I'm getting sick." (PLWH, Cleveland, USA).

Other PLWH defined their health by the way they felt, both mentally and physically. They saw themselves as healthy if they felt healthy, and illustrated these definitions by sharing what they do to feel healthy mentally and physically. Among the actions discussed, diet and exercise were often described as avenues toward achieving health because they promoted feeling of being well, and eliminated feelings of being unwell: "I like a lot of walking, 'cause the more I circulate- the less fatigue I feel, and the healthier I feel." (PLWH, Boston, USA). PLWH made clear associations between their definition of health and the desire for longevity, expressing an understanding that HIV can potentially limit their lifespan. Diet and exercise were discussed as a way of living that promoted the ability to live longer, and were crucial to achieving health from a perspective of longevity: "(HIV) makes you more aware of being healthy and eating well and doing the right things to keep going and living. Because that's the whole goal, is to live more." (PLWH, Boston, USA).

Providers and healthcare team members discussed the efforts they made to help their patients achieve health, which often corresponded to defining health as prevention of disease and promoting longevity. Diet and exercise were discussed as tools they provide to their patients to help them live longer and avoid comorbid conditions: "[We give them] exercise and nutrition programs so that they reach a healthier weight, because it won't only help them with their health, it will also help with cardiovascular comorbidities." (Healthcare team member, Puerto Rico).

Other providers defined their patients' health through their observations that patients demonstrated physical, emotional, and social progress. For example, one provider discussed gauging her patients' health by observing their progress after counseling them at visits about medication adherence, eating well, and exercising:

"What convinces me that (an) intervention was successful is that the patient keeps coming back to the clinic, you see them get better physically and emotionally even though you give them the same speech during each visit about medications, protecting themselves, eating well, etc." (Provider, Puerto Rico).

3.4. Perceived importance of diet and exercise

The way PLWH perceived diet and exercise was often discussed in the context of how important these self-management behaviors were to them. All of the participants in the study took medication for HIV, a behavior they knew underpinned their health. They illustrated their perceived importance of diet and exercise through comparisons to these pharmacological therapies. In some cases, participants expressed the belief that diet and exercise were as important, and even more important, than medications to being healthy:

"I've been undetectable now for 16 years, once was full-blown (AIDS), and (a television personality) was talking about certain things to eat to heal the body and I started eating my brown rice, garlic and onion to heal this disease" (PLWH, Cleveland, OH).

Others, however, believed that diet and exercise were not as important as HIV medication and HIV-specific disease indicators that they discussed with their providers. Other participants shared a different perspective, believing that HIV medications and HIV-related indicators were more important than diet and exercise: “I really don't care about any of it...I don't watch what I eat. All I do is just take my medicine on time. If I want to go out to the bar, I go to the bar. If I want to go eat pizza every night, I eat pizza” (PLWH, Cleveland, USA).

Finally, there were participants who did not believe that either medication or diet and exercise were more or less important, but rather, were both integral components of health of which they needed to be vigilant.

“You are what you eat, and to me foods are just as valuable than even some of the meds that we take, and certain things I just don't eat.” and “(Walking)helps me with my medications, it helps me with my stress, and I'm 100% into the treatment.” (PLWH, Boston, USA).

Providers shared that diet and exercise counseling were integral to their treatment plans with their patients. While they did not express opinions of the importance of diet and exercise in general, they expressed the importance in the context of their care and treatment interactions. Multiple providers discussed their recognition of the large number of health concerns that PLWH cope with, and that prioritization and importance of health behaviors outside of controlling HIV infection vary for individual patients. As one provider described the need to take small steps toward overall health goals:

“(I recognize) the complexities of this individual's outside life and competing priorities, so, you know, let's start this person on a multivitamin and work with adherence to the multivitamin..., you have to sort of parcel and build up to the ultimate education goal. But you have to start in small pieces.” (Provider, Boston, USA).

3.5. Competing needs

Participants from all groups discussed that PLWH face numerous challenges, and shared that there are times where their needs compete with each other. PLWH shared the competing health needs they felt, providing insight on how other issues may get in the way of being healthy. For example, addressing life stressors was commonly discussed as a competing need and had connections to diet and exercise behaviors. One participant shared: “I heard stress could break down the immune system quicker than anything...now I have a psychiatrist I talk to [about stress]. It's about me today, and if you can't understand that, oh well.” (PLWH, Cleveland, USA). Another participant shared, “I went to the doctor...and she said ‘your blood pressure is fine but you're gaining weight’, and she asked me why. I told her I'm very stressed. When I get stressed, I eat more than I usually do...I know what to do to take the weight off, but it's something that I have to do for myself.” (PLWH, Wilmington, NC, USA).

Providers also discussed the role of competing needs in the lives of their patients. They recognized that their patients may have needs that they give higher priority to

than health behaviors. The patients, the shared, may have not only multiple health concerns but also socioeconomic barriers that can impede the patient's ability to engage in self-management behaviors. One provider shared about unhealthy eating habits among her patients, “[My patients] are eating what is available, that's why [they] get diabetes [and] high blood pressure, because most of them, those [eating habits] are not changed” (Provider, Botswana). While the providers and healthcare team members shared the actions they took to encourage diet and exercise in their interactions with patients, they also recognized that they must also consider the competing needs their patients experienced. These provider and healthcare team experiences helped us to understand contextual factors that may drive participation or lack of participation in health diet and exercise behaviors by PLWH. One provider shared: “There's multiple barriers, there's physical, there's homelessness...mental health, drug abuse.” Another shared similar insight: “Some patients will tell you that they can't adhere because they don't have anything, no food, nothing.... A home probably trumps (worrying about) the cholesterol.”

3.6. Provider influence

There was strong agreement among participants that providers play a central role the perceptions PLWH have about diet and exercise self-management behaviors, and provided context for their engagement in such behaviors. PLWH often discussed provider advice as crucial to directing their health behaviors. As two participants shared:

“I just want to know ‘Doctor, let me know when it's really time for me to start eating right and doing right.’ I hope I don't wait too late...”; “When the doctors tell me to do something, I follow through, be it diet, exercise, whatever it is they need me to do. Even when I'm not feeling well...my best thing is going with the flow with the doctors.” (PLWH, Boston, USA).

In some cases, PLWH described health beliefs that were changed after a discussion with a provider:

“I thought if I was taking this high blood pressure pill that I could eat anything I wanted...(and) these pills are gon' take care of it, and (my doctor) was like ‘That's not the way it goes. That's not the way it goes.” (PLWH, Cleveland, USA).

Others shared similar stories, in which they adopted a healthy behavior after interactions with their provider: “When (my doctor) said ‘You're gonna have a heart attack,’ I went on my own diet and I lost (weight). I was scared. I didn't want to have a heart attack.” (PLWH, Cleveland, USA).

Providers described how they integrated diet and exercise information into their patient visits including the range of available programs and how they encouraged PLWH to take advantage of these programs. Providers also discussed the importance of tailoring their approach to diet and exercise counseling to individuals, and shared methods that they found successful:

“Using the food that we get from the pantry and cooking it in front of them....Seeing it from beginning to end how they turn the parts into an actual working element is

much more effective. And then individually, I usually get them to talk more....you just got to empower them.” (Healthcare team member, New York City, USA).

Another provider described educating her patient about fast food: “Whenever I see [my patient], he'll say, “I can't believe (a burger)is 750 calories!”... You know, whether or not he eats one, I don't know. But it stuck. He knows it.” (Provider, Boston, USA).

4. Discussion

The data from our multinational sample of PLWH and their health care providers indicate that though many PLWH and their health care providers perceive exercise and eating a healthy diet are important, the prioritization of such behaviors is largely based on context. This is the largest qualitative study to date investigating the perspectives and context of diet and exercise among PLWH. For the first 30 years of the HIV epidemic, the field has rightly focused on how to prevent HIV transmission and immunosuppression in PLWH. As such, the critical message of adhering to HIV medications was imprinted on many PLWH. Our data demonstrate that for some patients, HIV has become the central or perhaps the only health issue that they felt needed regular management. Exercise does not directly influence immunological or virological outcomes in PLWH (O'Brien, Tynan, Nixon, & Glazier, 2016) and the role of diet on these outcomes is mixed (Tang, Quick, Chung, & Wanke, 2015). Furthermore, our data suggest that some PLWH prioritize behaviors that improve HIV-specific outcomes. In contrast, other PLWH believed that adopting an overall healthy lifestyle, which included eating a healthy diet and engaging in exercise, contributes to the effectiveness of their HIV medication, and is crucial to achieving health and longevity. This integrated perspective is consistent with recent guidelines for HIV care that emphasize the need for a healthy, balanced diet and regular moderate-to-vigorous exercise for PLWH of all ages (Association, N. L., 2015, Gazzard et al., 2008).

HIV health care providers identified another aspect influencing whether and how eating a healthy diet and exercise are prioritized for PLWH, their socioeconomic situation. The socioeconomic barriers to engaging in exercising and eating a healthy diet listed by our health care providers, including homelessness, mental health, and substance use are complex challenges that may be uniquely prevalent to this population in higher-resource settings. The intersection of HIV, substance use, and mental health is associated with negative HIV outcomes including lower rates of viral suppression and higher care utilization (Robinson, Knowlton, Gielen, & Gallo, 2016). Robinson et al.'s (2016) recommendation to support comprehensive approaches to HIV interventions that help address multiple issues impacting health outcomes, in this case, engaging in a healthy diet and regular exercise, may be helpful in designing interventions to improve these critical behaviors (Robinson et al., 2016). Additionally, participants emphasized the significance of a healthy diet more than physical activity, as health promotion strategy. This may reflect two issues in HIV care today. First, access to healthy, consistent food is a necessity and in communities with severe deprivation, like many of the ones PLWHI come from, lacking food takes precedence to engaging in physical activity as a health promotion strategy. Second, many participants were recruited from clinics that have a nutritionist on staff. Consequently, PLWH and providers in these settings have

more exposure to diet messages than physical activity. However, as the evidence supporting physical activity as a critical non-pharmacological strategy to improve many aspects of health (e.g., cardiovascular disease, cognition) in this population grows, efforts can be made to incorporate physical activity into regular HIV care.

In addition to perceiving exercise and diet as part of an overall health promotion paradigm, participants utilized these strategies to manage their symptoms. PLWH experience a high symptom burden that can be hard to manage, but can be improved with engagement in healthy self-management behaviors such as exercise (Barroso and Voss, 2013, Pence et al., 2015, Watkins and Treisman, 2015). In addition to improving health, developing interventions that help PLWH engage in regular, moderate-to-vigorous exercise and eating a healthy, balanced diet, are likely to have a significant effect on symptom burden. We see this in other highly symptomatic populations including those living with heart failure and those undergoing cancer treatments (Belardinelli et al., 2012, Blumenthal et al., 2012, Cheville et al., 2013, Courneya et al., 2013, Keogh and MacLeod, 2012, Pandey et al., 2015, Puetz and Herring, 2012). Although interest in this area is growing (Ances, 2015, Jemmott, 2013, Moore, 2015, Waldrop-Valverde, 2016), we currently lack effective evidence-based interventions tailored to PLWH that will facilitate long-term behavior changes.

Finally, our data clearly describe the prominent role that trusted health care providers have when integrating health promotion (e.g., exercise and nutrition prescriptions) into routine HIV care. PLWH held their health care team in high esteem and valued their counsel. Health care providers indicated that helping patients engage in eating a healthy diet and regular exercise was important yet HIV health care providers have historically focused on managing HIV disease through medication (Rose et al., 2012). Our results indicate that providers can leverage their strong patient relationships to emphasize a holistic concept of well-being that includes healthy diet and exercise behaviors. For example, providers described tailoring some of their advice to individual patients, but did not describe a systematic approach to regularly assessing and recommending exercise and diet behavior. A systematic approach to assess, recommend interventions, and follow-up on behavior changes will emphasize the importance of these behaviors for PLWH and produce meaningful change.

Our study has several strengths including drawing from a large, heterogeneous, multinational sample of PLWH. We also draw on the direct experiences of PLWH and their health care providers, which provides us with a fuller understanding of the perceptions and context of diet and exercise among PLWH around the world. However, our study also has limitations. Despite a large amount of rich data, as a secondary analysis, the study was not primarily designed to understand the perspectives and context of diet and exercise among PLWH and their health care providers. Consequently, we were unable to ask additional probing questions regarding these phenomena, leaving gaps in our understanding about the contextual drivers of these behaviors. Specifically, we were unable to examine how the built environment influences diet and exercise behavior. Given recent work documenting the importance of the environment on physical activity (Sallis et al., 2016), future work should examine this relationship and determine if there is a

differential impact of the environment on these behaviors in PLWH compared to healthy, well-resourced populations.

5. Conclusion

Despite the rapid rise of chronic comorbidities in PLWH, we found that for some PLWH, HIV remains the central health issue. PLWH recognize the positive impact that a healthy diet and exercise have on managing their health and symptoms, but have a hard time meeting national guidelines due to contextual factors. Finally, we describe the significant, and often underutilized role that primary HIV health care providers have in supporting PLWH to make improvements to their exercise and diet behavior. Though additional research is needed, our study helps solidify a foundation for new research supporting a holistic wellness-focused paradigm for aging PLWH engaged in care, which will help to stem the growing tide of comorbidities in PLWH worldwide.

Acknowledgements and funding

We'd like to acknowledge Starr Hilliard for her contribution of initially coding all transcripts, Jan E Hanson and Lauren Starks for their assistance in data collection, and all of the generous participants who contributed to this study.

This work was supported in part by the National Institutes of Health under Grant T32 NR007081, Portillo, 5T32NR014213 and under Grant K24DA037034; the Irwin Belk Distinguished Professorship, the University of North Carolina Wilmington; the AIDS Funding Collaborative of Cleveland; the Human Resource Development Council in Gaborone, Botswana; and the University of Puerto Rico Central Administration Grant under grant MFP-6251123.

Table 1. Characteristics of the participants (n=206)^a

	PLWH (n = 135)	Health care providers (n = 32)	Health care team members (n = 39)
Age in years (SD)	48.0 (10.8)	45.4 (10.2)	42.7 (11.1)
Sex: Male (%)	68 (50.4)	6 (35) ^b	6 (27) ^c
Race/ethnicity			
African American/Black	60 (44.4)	10 (31.3)	6 (15.4)
Caucasian	30 (22.2)	11 (34.4)	20 (51.3)
Hispanic/Latino	23 (17)	8 (25)	3 (7.7)
Other	20 (14.8)	3 (9.4)	10 (25.6)
Education			
Less than high school	35 (25.9)	0	0
High school degree or equivalent	49 (36.3)	0	0
2 years of college/associate's degree	28 (20.7)	0	13 (33.3)
Bachelor's degree or higher	15 (11.1)	32 (100)	26 (66.7)
Currently employed (%)	47 (34.8)	32 (100)	39 (100)
Health characteristics			
Years living with HIV	15.1 (7.9)		
Have other health conditions ^b	95 (70.4)		
Currently taking HIV medications	106 (78.5) ^d		

^aAll data presented as Totals (Means), unless otherwise noted.

^b17 out of 26 participants responded to this question.

^c22 out of 39 participants responded to this question.

^d76 out of 120 participants responded to this question.

Table 2. Theme, definition and variations among participants

Theme	Definition	Variations/subthemes among people living with HIV	Variations/subthemes among HIV health care providers
Defining health	The ways in which PLWH and providers discuss health and wellbeing	<ol style="list-style-type: none"> 1) Subjective feeling/affect 2) Absence of disease 3) Longevity 	<ol style="list-style-type: none"> 1) Affect 2) Absence of disease
Perceived importance of diet and exercise	The ways in which PLWH and providers prioritize diet and exercise	<ol style="list-style-type: none"> 1) HIV medication only 2) Diet and exercise added to HIV medication regimen 3) Diet and exercise emphasized 	<ol style="list-style-type: none"> 1) HIV treatment first step towards a healthy life 2) Diet and exercise integral
Competing needs	Other priorities that hamper – or are seen as alleviated by (e.g., stress) – diet and exercise	Psychosocial stressors	Socioeconomic needs (e.g., homelessness, mental health comorbidities)
Provider influence	The ways in which healthcare providers influence diet and exercise among PLWH as discussed by both providers and PLWH	Change after straightforward healthcare interaction	Emphasis on tailoring diet and exercise education to the individual

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