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# "I don't want to look sick skinny": Perceptions of Body Image and Weight Loss in Hispanics Living with HIV in South Texas

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## Abstract

**Objective:** Obesity is rising in people with HIV (PLWH) and Hispanics. Both HIV and obesity are associated with cardiovascular disease morbidity and mortality. Our goal is to understand perceptions of body image and lifestyle in Hispanics with HIV to adapt interventions appropriately.

**Methods:** We conducted semi-structured interviews with 22 Hispanic PLWH and 6 providers. Purposive sampling selected patient participants across weights and genders. Interviews were coded and analyzed using grounded theory, comparing perspectives between patients with and without obesity, and patients and providers.

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**Results:** Participants felt obesity and diabetes were “normal” in the community. Patients exhibited understanding of healthy diet and lifestyle but felt incapable of maintaining either. Traditionally Hispanic foods were blamed for local obesity prevalence. Five patients equated weight with health and weight loss with illness, and four expressed concerns that weight loss could lead to unintentional disclosure of HIV status. Participants with overweight or obesity expressed awareness of their weight and felt shamed by providers. Providers found weight loss interventions to be ineffective.

**Conclusion:** Interventions in this population must address identified barriers: overweight/obesity as a normative value, lack of self-efficacy, cultural beliefs surrounding food, fear of HIV-associated weight loss and stigma, and provider perspectives on intervention futility.

### Keywords

HIV; obesity; Hispanics; Body Image; Lifestyle modifications

## INTRODUCTION

The prevalence of overweight and obesity in people living with HIV (PLWH) is rising, a product of our success with antiretroviral therapy and the transformation of HIV into a chronic illness. People receiving potent antiretroviral therapy anticipate living a near-normal lifespan, and 2015 marked the first year in which the average age of those living with HIV in high-income countries is 50 years old (Samji et al., 2013; World Health Organization, 2013). Chronic HIV infection is associated with an increased risk of cardiovascular disease (Islam, Wu, Jansson, & Wilson, 2012; Sackoff, Hanna, Pfeiffer, & Torian, 2006; Triant, 2012; Triant, Lee, Hadigan, & Grinspoon, 2007). This additive cardiovascular risk, combined with the aging of people living with chronic HIV infection, means that healthy lifestyle choices are essential to help reduce cardiovascular risk for PLWH. A key tenant of successful behavioral change intervention implementation is the assessment of stakeholder perspective and context (Damschroder et al., 2009; Damschroder & Lowery, 2013; Peters, Tran, & Adam, 2013). The goals of this investigation are: 1) to understand how people living with HIV perceive body image, lifestyle changes, and cardiovascular risk, and 2) to determine the views of providers who would implement the intervention on the efficacy of behavioral and lifestyle interventions for weight loss. Both are critical steps prior to intervention design.

Individuals of Hispanic ethnicity, particularly those of low socioeconomic status living in the Southern United States (U.S.), are at increased risk for obesity when compared with non-Hispanic whites or those living in the Northeast or Western U.S. (Flegal, Carroll, Ogden, & Curtin, 2010; Ogden, Carroll, Kit, & Flegal, 2012, 2014; Wang & Beydoun, 2007). The “Hispanic paradox”, a higher prevalence of cardiovascular risk in Hispanic populations when compared with non-Hispanic Whites but a lower rate of cardiovascular events, is well described in the literature and found across many large cohort studies (Cortes-Bergoderi et al., 2013). However, National Health and Nutrition Examination Survey (NHANES) data suggest that waist circumference is highly predictive of all-cause mortality and diabetes-related mortality in Mexican Americans (Howell et al., 2018). These data suggest a high risk for obesity and obesity-related complications in Hispanic communities.

Unfortunately, Hispanics in the U.S. South are also disproportionately impacted by the HIV epidemic, with increasing incidence and prevalence of HIV infection when compared with non-Hispanic whites (Reif et al., 2014; Rosenberg, Grey, Sanchez, & Sullivan, 2016; U.S. Center for Disease Control and Prevention, November, 2016. Accessed August 25, 2017.). This overlapping risk is reflected in a growing prevalence of Hispanics with obesity/HIV comorbidity (Koethe et al., 2016; Taylor et al., 2014; Thompson-Paul et al., 2015). In our own work, we found that Hispanics and African Americans in South Texas who were living with HIV and without insurance were more likely to have significant weight gain over time than insured non-Hispanic whites (Taylor et al., 2014). These data imply that the prevalence of obesity/HIV comorbidity is likely to increase, particularly in underserved Hispanic populations in the Southern U.S.

Hispanics with HIV may also face structural barriers to weight loss and the adoption of healthy lifestyles. Overweight Hispanics are less likely to perceive themselves as overweight,(Burke, Heiland, & Nadler, 2010; Langellier, Glik, Ortega, & Prelip, 2015; Naghshizadian et al., 2014; Twarog, Politis, Woods, Daniel, & Sonneville, 2016; Yan, Zhang, Wang, Stoesen, & Harris, 2009) and may have a higher target body weight than appropriate. They are less likely to participate in physical activity,(Dai et al., 2015; Ladabaum, Mannalithara, Myer, & Singh, 2014) and less likely live in safe, walkable neighborhoods (Gordon-Larsen, Nelson, Page, & Popkin, 2006; Lightfoot & Blanchard, 2011; Watson, Harris, Carlson, Dorn, & Fulton, 2016). Weight loss interventions for Hispanics that involve intensive lifestyle intervention have been effective in some studies, (Marquez et al., 2016; O'Brien et al., 2017; Parra-Medina, Liang, Yin, Esparza, & Lopez, 2015; Van Name et al., 2016) but other efforts involving small change behavioral weight loss efforts or self-affirmation have been unsuccessful (Parra-Medina et al., 2015; Phillips et al., 2017). Finally, in communities where HIV is more prevalent, weight loss may actually be associated with HIV disease and stigmatized (Barroso, Peters, Johnson, Kelder, & Jefferson, 2010).

The increased risk of cardiovascular disease in people living with HIV is well documented. It is estimated that PLWH have approximately twice the likelihood of acute myocardial infarction compared to patients without HIV infection (Paisible et al., 2015; Triant et al., 2007). This increased risk of cardiovascular disease for PLWH is observed even after controlling for age, dyslipidemia, hypertension, diabetes, and use of antiretroviral medications associated with cardiovascular risk (Cerrato et al., 2015; Freiberg & So-Armah, 2016). The increased cardiovascular risk in PLWH is multifactorial. Use of certain antiretroviral medications, (FriisMoller et al., 2010) high prevalence of cardiovascular risk factors including smoking at baseline,(Centers for Disease Control and Prevention, 2017; Soliman et al., 2015) and increased levels of chronic inflammation all contribute (Freiberg & So-Armah, 2016). Unfortunately, despite the decreasing rate of all-cause mortality among PLWH, mortality due to cardiovascular disease is increasing (Feinstein et al., 2016). Despite the increasing prevalence of obesity/HIV comorbidity, structural barriers to weight loss and healthy lifestyle in the racial and ethnic minorities most impacted by the HIV epidemic, and the increased cardiovascular risk associated with HIV infection, little is known about the perceptions of body image, weight, and lifestyle interventions in Hispanics living with HIV.

There is also a gap in our understanding of the role HIV care providers play in supporting weight loss or lifestyle interventions for PLWH. Social workers, nutritionists, and medical practitioners play key roles in the weight loss interventions described above, and would be important stakeholders in the implementation of any weight loss program within a clinic. Studies of primary care providers indicate that barriers to discussing weight loss include: lack of time, perception that patient behavior will not change, insufficient knowledge, and discomfort with the subject (Simon & Lahiri, 2018). To our knowledge, there are no data on perceptions of weight loss interventions or barriers to intervention amongst providers caring for PLWH. From an implementation science perspective,(Damschroder et al., 2009; Damschroder & Lowery, 2013) understanding the perspective of these key stakeholders and their context is essential prior to the development of interventions for weight loss and lifestyle change in PLWH.

South Texas is an ideal setting in which to examine these issues. San Antonio is the largest city in South Texas with 1.5 million inhabitants, 63% of whom are Hispanic or Latino, mostly of Mexican American descent. San Antonio has a 70% prevalence of overweight/obesity, and the highest rates of un-insurance in the nation (Radley & Schoen, 2012; Ramirez, Munoz, Holden, Adeigbe, & Suarez, 2014; San Antonio Metropolitan Health District Epidemiology Program, 2016). Health disparities in San Antonio are geographically distributed, concentrating in lower income, majority Hispanic communities, which often lack public space for exercise and healthy food options (The Health Collaborative, 2016). These socioeconomic vulnerabilities, tethered to lack of access to care and high baseline obesity prevalence, can create barriers to healthy lifestyles (He et al., 2013; Parra-Medina et al., 2015). Despite community-wide efforts to encourage lifestyle change and weight loss, obesity rates in San Antonio continue to rise, and the prevalence of diabetes and complications from diabetes are some of the highest in the nation (Foster & Hale, 2015; Foster, Maness, & Aquino, 2017; SA2020, 2018).

We previously demonstrated a rising prevalence of obesity in Hispanics and African Americans living with HIV in San Antonio, particularly for those who were uninsured (Taylor et al., 2014). To more appropriately adapt interventions to the needs of people living with HIV in this setting, we assessed perceptions of body image, healthy lifestyle, diet, and local norms amongst Hispanics in different weight categories living with HIV and their providers in the largest public HIV clinic in South Texas. We hypothesize that Hispanics living with HIV have barriers to weight loss derived from both structural influences and HIV-specific stigma, and that patient and provider perspectives on lifestyle interventions will differ.

## METHODS

### Study Design and Participants

A qualitative study using in-depth interviews was conducted to explore perceptions of body weight and healthy lifestyle behaviors in Hispanics living with HIV receiving care and their providers in a South Texas HIV primary care clinic serving over 3500 individuals. Grounded theory was used to guide analysis to gain a deeper understanding of the HIV-obesity comorbidity in this population (Glaser & Strauss, 1967; Iman & Manizeh, 2008).

For patient participants, inclusion criteria were: living with HIV (PLWH), self-identify as Hispanic, at least 18 years or older, body mass index (BMI) ≥18.5kg/$m^2$, and English speaking. Of 33 participants approached for interviews, 22 accepted and were included in the study. Though the clinic asks people to self-identify only as Hispanic vs non-Hispanic, PLWH included in this sample reflected the expected clinic demographics: 20 of Mexican American origin born in the U.S., one born in Mexico, and one born in Puerto Rico. We chose to focus on Hispanics because our prior work showed uninsured Hispanics were most at risk for overweight/obesity and weight gain (Taylor et al., 2014). Focusing on a single racial/ethnic minority group allowed for a focused exploration of structural barriers and a more manageable sampling design.

We also chose to exclusively focus on participants who could speak English, because existing literature on the impact of acculturation and language barriers on weight and lifestyle suggests that combining English-dominant and Spanish-dominant Hispanics in the same sample would inappropriate,(Stein, Trabold, & Connelly, 2017; Valdez, Amezquita, Hooker, & Garcia, 2017) and the recruitment and participation of an additional 20 or more Spanish-speaking PLWH was beyond the resources and scope of this investigation. As the majority (90%) of Hispanics living with HIV in San Antonio are English-dominant, we limited our scope to this population.

Those with an underweight BMI (<18.5kg/$m^2$) were excluded because the study goal is to focus on perceptions of and barriers to weight loss in the context of reducing HIV/obesity comorbidity, and weight gain is an appropriate priority for underweight patients. We included normal weight participants because their success in maintaining a healthy weight in a context where the norm is overweight or obesity may provide insight into strategies for weight management for those with overweight or obesity.

One investigator screened consecutive patients presenting for routinely scheduled clinic visits to determine whether they met inclusion criteria. Hispanic ethnicity was determined by demographic profile in the electronic medical record and established at enrollment by patient self-identification. Purposive sampling was used to ensure adequate representation across three categories of weight and gender/sexual orientation, identifying potential participants in each strata based on chart review.

Provider participants were recruited from the same HIV primary care clinic, and were selected to gain insights from a diversity of providers, with varied backgrounds, roles, and skill levels, that might address weight and body image within the clinic and in order to gain a diverse range of viewpoints. Providers' perspectives were solicited to help the investigators understand clinic and provider-level barriers to lifestyle intervention. Six providers were included: 1 physician, 1 nurse practitioner, 1 physician assistant, 2 social workers, and a nutritionist. Three of the six providers, including the physician and the nurse practitioner, are of Hispanic ethnicity (one Puerto Rican and two Mexican American in origin), the remainder are Anglo/Caucasian. All providers are women except for a male nutritionist and case manager. The medical provider experience ranged from 2 to 17 years in the clinic, and non-medical providers ranged from 1 to 6 years.

## Study Procedures

Two semi-structured interview guides, one for patients and one for providers, were informed by previous research on body perception, race/ethnicity, and HIV status, and the combined experience of the investigators (Foster & Hale, 2015). For both patient and provider participants, individual (one on one) interviews were conducted in a private space within the HIV clinic.

**Patient participant interviews.—**Individual semi-structured interviews allowed the interviewer and participant to discuss a specified set of topics and permit exploration of new themes as the conversation progressed. Demographic characteristics were collected including housing, employment, shopping and transportation arrangements, as well as romantic and sexual relationships. Interview questions explored patient participants' perceptions of body image, weight loss and gain, as well as the impact of Hispanic or South Texas culture, family on behaviors like exercise and dietary choices/intake.

The interviewer initially asked about the participants' demographics then asked about eating habits and food preferences: "Tell me about the types of foods you like to eat," and "Do you prepare the food or does someone cook for you?" and "Do you share meals or eat on your own?" Participants were then asked about perceptions of a healthy diet and Hispanic foods: "What is your idea of a healthy portion?" and "Do you think you eat healthy?" and "How do you think Hispanic food can be made healthier?" Next, participants were asked about body image and healthy lifestyle: "What do you think about your current weight?" and "What is your idea of a healthy weight?" and "Do you want to change your weight?" Next, the interviewer asked about attempts to change weight: "Have you tried to gain or lose weight before?" and "What methods did you try?" and "How do you think you would maintain these healthy changes?" and "Has a doctor ever told you to change your weight and what did you think about that?" Participants were also asked about the circumstances around how they were diagnosed with HIV: "How did you know to get tested?" and "Did you lose weight with your initial diagnosis?" and "Are you taking medications for HIV?" and "Do you think the HIV medications have changed your body?" The interview guides were reviewed by the investigators and iteratively revised throughout the data collection period to address new themes or questions as they arose during the interviews. Interviews, which lasted 30–60 minutes, were conducted by a single investigator who was completing his Infectious Disease Fellowship at the time of the interview and was not a provider for any of the participants included in the study.

When discussing body weight and desire for weight loss or gain, patients were asked to select their current perceived body habitus and goal body habitus silhouette on a Stunkard scale specific to their gender. Each scale has nine figures numbered 1–9 with 1 being the most slender and 9 being the heaviest. The scale has been validated in a variety of populations including one in Mexico (Kaufer-Horwitz, Martinez, Goti-Rodriguez, & Avila-Rosas, 2006; Stunkard, Sorensen, & Schulsinger, 1983). From that study, silhouettes 1–4 correlated with a normal BMI, silhouettes 4–6 with overweight BMI and silhouettes 6–9 with an obese BMI (Kaufer-Horwitz et al., 2006). Using the patient participants' Stunkard

scale results, the medians of current and goal body habitus were calculated overall and by BMI category.

**Provider interviews.—**For the provider interviews, questions varied somewhat by provider role, for example, the questions posed to the dietitian explored his intervention strategies, while questions posed to case managers determined the role they play in motivating patients to adopt lifestyle change or take advantage of existing resources. All interviews focused on the role of the provider in the clinic and in lifestyle/weight loss counseling, perceptions of patients' desire to lose or gain weight, counseling methods, and perception of effectiveness of weight loss counseling. Specific questions covered perceptions regarding patients' motivations for weight loss and perceptions of weight in the context of South Texas, for example: "What motivates patients to lose weight?" "Studies have shown many patients who are overweight are not aware of their weight status, what factors do you think play a role in this?" "Do you think there are different cultural perceptions/attitudes towards of obesity?" A second series of questions explored barriers to weight loss or lifestyle interventions within the clinic: "What barriers exist in educating patients about obesity and developing a management plan for them?" "What resources exist within the clinic for interventions?" "Are there any costs for weight loss and lifestyle interventions?" "What approach do you think is effective?" Interviews lasted 30–60 minutes and were conducted by the same trained investigator who conducted the patient interviews.

## Data Analysis

Interviews were audio recorded and transcribed verbatim by a member of the study team. Transcripts were read by the interviewer and compared with the audio recording to assess for quality and errors. Grounded theory, including a process of open coding, axial coding, and then selective coding, was used (Glaser & Strauss, 1967; Iman & Manizeh, 2008). Three members of the study team iteratively reviewed all interview transcripts during, and after, the data collection phase of the study. The purpose of this iterative process was to develop a comprehensive codebook, until a reliable coding scheme was established. Transcripts were uploaded into ATLAS.ti (version 7) for analysis. The initial codebook was used by two investigators to independently code each transcript in ATLAS.ti, generating new codes as needed. The coded datasets were then merged and differences were reconciled as needed in discussion between the three members of the study team, until agreement was met. Once open coding had been completed, these same three members collapsed codes, and created analytical categories, through the process of axial coding. The researchers discussed the appropriateness and theoretical relevance of each open code and its inclusion in each analytic category. Selective codes were than created through a discussion regarding the theoretical relationships between each of the axial codes. Open axial codes were also examined by BMI category in order to assess whether differences emerged in perspectives by weight category, and by patient/provider status to determine discrepancies in perceptions of body weight or intervention between these groups. Exploratory analyses of the impact of sexual orientation and provider race/ethnicity on the axial codes did not reveal significant differences in themes for between these groups.

### Ethical Oversight

All procedures performed in studies involving human participants were in accordance with the ethical standards of the institutional and/or national research committee and with the 1964 Helsinki declaration and its later amendments or comparable ethical standards. The University of Texas Health Science Center San Antonio and University Health System Institutional Review Boards approved the study. All participants provided informed consent to be audio recorded and for study participation. Patient participants were compensated $10.00 per hour of their time. Providers were not compensated.

## RESULTS

### Patient Participant Characteristics and Body Image Perception

Of the 33 participants approached for interviews, 22 (67%) accepted and were included in the study. The median age was 44.5 (IQR: 30.5, 52.0) years. Four were uninsured and the rest had either private or government-sponsored coverage (Medicare/Medicaid). Half of patient participants were in committed relationships (n = 10) and nine had children; 11 (50%) were currently employed. Median income was $1500/month (range $0 to $12,917/month and three declined to answer). Two patients met clinical criteria for AIDS with a CD4+ cell count less than 200 cells/$mm^3$. Sixteen (73%) had controlled HIV disease with HIV-1 plasma RNA levels under 20 copies/ml and one did not have a recent HIV-1 plasma RNA level measurement (Table 1).

Both normal weight (n=7) and overweight (n=6) participants rated their current body image in the range of 5 and 5.3, respectively, on the Stunkard scale, which is associated with an overweight BMI. Participants with obesity (n=9) rated their current body image a median of 6.5, which correlates to BMI ≥30kg/$m^2$. Overall, all participants rated their goal body image as a median of 4, which correlates with an overweight BMI (Table 2).

### Significant Themes Impacting Perceptions of Obesity and Body Image for Patients

Significant themes identified from patient participant interviews were organized into eight nonHIV-specific and three HIV-specific themes (Table 3). Non-HIV specific themes are relevant to the local population and would not be expected to be related to an HIV diagnosis: dominant food culture, food and family, obesity as a community norm, childhood food access, knowledge base, work environment, cost of healthy food, and lack of time. HIV-specific themes were those judged by the investigators as less likely to be found in the general population and not present in the literature review of body image perceptions in HIV-negative populations: the association between thinness and illness, the concept of additional weight as protective buffer against future illness, and that excess weight hides HIV-related body changes such as lipodystrophy.

### Non-HIV Specific Themes

**Dominant food culture:** When asked why obesity rates were higher amongst Hispanics, nearly every participant mentioned Mexican-American foods. Tortillas were the most frequently cited (n=15) food thought to contribute to obesity. The use of oils and lard in

cooking were also mentioned. The majority of patients thought common regional foods (eg. tortillas, tamales, barbacoa) could not be modified without sacrificing flavor.

> It's like a cultural thing. It's absolutely true um, you know. In San Antonio you can find tacos anywhere.

**Food and family:** Four (one with obesity, three normal weight) participants cited that sharing meals with family was associated with an inability to eat healthily, as other family members were unwilling to modify their diets.

> [My family has] so much food. That's how they show that they care about each other.

> They [his family] think that if it's just broccoli and carrots and a potato, they're like, "What's that?" I'm like, "That's my lunch." I'm the only one who would eat healthy basically. They like all this Mexican food, full of grease and bad things.

**Obesity as community norm:** Many participants felt that obesity and diabetes are "normal" in the community or within their family. Some described them as inevitable, with fatalistic language, with underlying lack of self-efficacy.

> I think that a lot of people have seen themselves like their parents and their uncles. Or whoever have diabetes. So it's kind of like. Instead of thinking, what can I do to not have it, they kind of feel like they're going to get it.

**Childhood food access:** When asked about childhood weight and dietary habits, participants acknowledged family norms influenced by poverty and food access (n=6). These included lack of vegetables or healthy food, and the practice of eating as much as they could at any meal because of food insecurity.

> My up bring was never any fruits or vegetables, because I pretty much. Or healthy eating. I'd pretty much learned that on my own.

**Knowledge base:** Nearly every patient (n=21), regardless of weight category, exhibited appropriate understanding of healthy lifestyle. This included knowledge of portion control, balanced meals, calorie counting, and regular exercise. The participants cited the Internet, nutritionist appointment, school and magazines as resources. Some participants felt that healthy eating meant having a bland or boring diet.

> On portion size: "They say, if it fills in your hand or something."

**Work environment:** Work environments led to snacking, through continuous availability of sweets or other unhealthy foods. Long work hours that do not leave time for healthy food preparation were seen as barriers to healthy eating.

> It's just snacking, cause, there's no time to leave to go get food or anything like that, because I'm stuck at work

**Cost of healthy food:** Participants acknowledged that healthy food is more expensive than unhealthy food, and, at times, these costs were prohibitive.

If you look at it now, it's expensive to eat healthy.

**Lack of time:** Healthy eating, dieting, and exercise all require some preparation, which most patients said they were lacking.

It's more fast food places, because I'm always in a rush. I need to get in and out.

### HIV-specific Themes

**Thin = ill:** Eight participants (three with obesity, four with overweight, one with normal weight (BMI ≤25kg/$m^2$)) expressed fear of weight loss during the interview. Six of the eight reported losing a significant amount of weight in the course of their illness either due to AIDS, opportunistic infections, drug use, or prison time. These participants differed from the overall group in that they equated weight loss with sickness, and five of the eight participants verbally expressed a preference for a larger body habitus as they equated weight with health. This fear of weight loss was not reflected in the body image scale, as desired body image for these participants was the same as other participants (Stunkard scale = 4).

Because when I get Histoplasmosis, I get my, my bones was to the skin…. Because I seen myself as skinny, and I don't want to be skinny any more… Not as skinny, but like sick skinny. No, that's why I always prefer to have a little weight.

**Weight as a buffer against future illness:** A few patients expressed a desire to be overweight so that they would have some weight to lose if they became sick again.

I guess because of my HIV. And, you know I'm going to end up in the hospital again, or something like that. So that's why, you know what I mean. I start to try to eat more, and more.

**Weight hides HIV-related body changes:** Four patients (two with obesity, two with normal weight) expressed concerns about weight loss as it might lead to unintentional disclosure of their HIV status, and that people would be able to tell that they have HIV if they were to lose weight or become thin. Several patients (n=3) mentioned concerns about the sunken facial features and increased central obesity classically associated with HIV and HIV medications.

My cheeks got sucked in and I know that's part of the HIV and stuff. But you can never see. You can never tell on me, but when, when I'm that thin you sure can.

### Differing Perceptions of Weight and Body Image for Patients by BMI Category

Comparative analysis of themes by BMI category revealed key differences between those with normal weight and those with overweight or obesity.

**Shame from providers:** Patients with overweight or obesity expressed a general awareness of their weight, and often felt chastised by providers for their weight. This feeling did not vary by race/ethnicity of the provider, and was endorsed by participants with both Hispanic and nonHispanic medical providers.

**Healthy lifestyle techniques:** Patient participants who were normal weight or who successfully lost weight were more likely to describe using a variety of methods to maintain healthy weight. Five (three with obesity, two normal weight) of the participants used health applications on their smartphone, (e.g. LiveStrong and MyFitnessPal). Four (one with obesity, three normal weight) participants cited their families as barriers to healthy eating, and found that to lose weight or maintain normal weight they had to shop, prepare, and eat food separately.

> I eat separate… They don't eat the way I do, so when they go shopping or whatever for their food, they buy what they eat. Then I usually go about every Friday. Once a week, every Friday, I'll go shopping for my food.

Only one of the overweight participants shared such lifestyle modification strategies, which were shopping, preparing and eating food separately to avoid the temptation of eating unhealthy foods.

## Barriers to Intervention Unique to Providers

Several themes emerged when providers were asked to identify barriers to effective weight loss intervention for their patients. Many of the themes identified in patient interviews were echoed, including: the dominant food culture being unhealthy, the link between food and family, and the high cost of healthy foods. Several unique themes also emerged including (Table 4):

**Counseling is ineffective:** Three providers expressed a fatalistic attitude towards obesity counseling and found it to be generally ineffective. Providers said they placed a low priority on healthy lifestyle counseling. Providers could recall only one or two patients who had effectively lost weight.

> The sample size of those patients who have tried to lose … is relatively small. I can probably count them on one hand.

**Patients not motivated to change:** Other barriers cited were lack of motivation and low self-efficacy. Five providers mentioned that patients, particularly women with overweight or obesity, asked to be evaluated for an underlying medical cause for their obesity or for a pill to help them lose weight.

> I think a majority of patients are not motivated to lose weight.

**Negative reactions to weight loss:** Providers mentioned responding to weight loss, even weight loss described as intentional by patients, by searching for an HIV-related cause including loss of virologic control and opportunistic infections.

> I would inquire about whether or not they've been sick…to try and figure out whether or not there is something, if they have not been trying to intentionally lose weight.

## DISCUSSION

To our knowledge, this is the first study to explore perceptions of body image and weight loss/lifestyle interventions among any racial or ethnic minority living with HIV and their care providers, though our findings are most relevant to majority Mexican American PLWH. Consistent with our hypothesis, participants expressed perceptions of weight found in prior studies of racial or ethnic minorities, specifically Hispanic or Mexican American populations, without HIV, including perceptions of: an “unhealthy” dominant food culture that cannot be changed, the connection between food and family dietary norms, and the high price and increased preparation time required for healthy eating habits (Barroso et al., 2010; Kaufman & Karpati, 2007). The results from the Stunkard silhouettes scale suggest patients desire an overweight body habitus, implying that overweight/obesity is a normative value in this population, as seen in minority groups not living with HIV (Barroso et al., 2010; Burke et al., 2010; Dorsey, Eberhardt, & Ogden, 2009). However, several novel themes emerged that were specific to PLWH, including a fear of weight loss associated with AIDS-related wasting, overweight/obesity as a buffer against future illness, and the desire for weight gain to mask HIV-associated lipodystrophy. Finally, providers expressed beliefs that weight loss interventions were ineffective and that patients were not motivated to make lifestyle changes required for weight loss. Collectively, these findings suggest that significant context- and HIV-specific barriers to weight loss and lifestyle change exist for Hispanics living with HIV in South Texas. We discuss each major finding in the context of the current literature below.

First, our findings regarding the perceptions of weight loss and impact of food culture in South Texas are consistent with studies of these issues in Hispanic populations without HIV. A qualitative study of the African American and Latinx teenagers in the Southwest revealed that “cultural eating,” or the consumption of palatable high fat foods, was the primary perceived determinant of overweight for Latinx youth (Barroso et al., 2010). Latinx youth also noted that growing up in poverty and food insecurity led their parents to associate eating with wealth and overweight with health. Poverty often limits options for healthy food, regardless of the ethnic origin of the food, and reduces time available to exercise (Barroso et al., 2010). A second study of low income Mexican American or Mexican immigrant families in South Texas found similar themes of collectivist/familism values within the Latinx culture and cost/time barriers to healthy lifestyles (Turner, Navuluri, Winkler, Vale, & Finley, 2014). All of these themes were present in our predominately Mexican American sample of PLWH. The food culture for our participants is dominantly Mexican American but is also influenced by unhealthy fast food and lack of access to inexpensive healthy options seen in many poor communities (The Health Collaborative, 2016). The impact of poverty and family networks on obesity and weight loss has been noted other Hispanic communities, as seen in an ethnography of families in Brooklyn of dominantly Dominican, Puerto Rican, and Mexican origin and a study of Latinx parents in San Francisco (Kaufman & Karpati, 2007; Penilla, Tschann, Sanchez-Vaznaugh, Flores, & Ozer, 2017). These data suggest that contextually/culturally appropriate lifestyle interventions are needed for Hispanics living with HIV in South Texas.

The theme of obesity being a normative value within our predominately Mexican American sample of PLWH is reinforced by the data from the Stunkard body image scale. Self-

perception of weight on the Stunkard scale was accurate for patient participants with overweight or obesity, but normal weight participants incorrectly selected an overweight silhouette as their current silhouette. All patient participants, regardless of weight category, selected an overweight silhouette as their goal body habitus. These data are interesting as the incorrect self-assessment of normal weight participants as overweight/obese was not seen in a large samples of urban adults in Mexico and Baltimore (Kaufer-Horwitz et al., 2006; Sutcliffe, Schultz, Brannock, Giardiello, & Platz, 2015). However, these data align with a study of predominately African American youth living with HIV, who reported contentment with current body size if they were overweight, and a desire for larger body size if they had normal BMI (Wilkins et al., 2016). In the study of African American and Latinx teenagers mentioned above, photos of overweight individuals were selected as goal body habitus by Latinx teenagers (Barroso et al., 2010). However, idealization of an overweight body habitus was not seen in other studies of African American, white non-Hispanic, and Saudi women, (Albeeybe et al., 2018; Carter-Edwards et al., 2010) and in Brazilian men and women (Mintem, Gigante, & Horta, 2015). The disconnect between weight and weight perception and the desire for an overweight goal body habitus seen in our study are concerning, as correct weight perception was positively associated with weight management behavior among Mexican American adults (Dorsey, Eberhardt, & Ogden, 2010).

Our study identifies several HIV-specific barriers to weight loss that are clinically relevant. Patients expressed fear of weight loss associated with AIDS-related wasting, the belief that overweight/obesity should be a goal as a buffer against potential future illness, and the perception that excess weight gain can mask HIV-associated lipodystrophy. Lipodystrophy is a visible, often stigmatizing, manifestation of an HIV diagnosis, and fear of these conditions has been common among PLWH since the inception of the epidemic (Santos et al., 2005). Much of the literature on body image in PLWH focuses on sexual minority men, where negative body image has been associated with depression and non-adherence to medication (Blashill, Goshe, Robbins, Mayer, & Safren, 2014; Blashill & Vander Wal, 2011). One of the few studies to focus on Latinx youth newly diagnosed with HIV found that body image and concerns regarding physical changes that might occur with initiation of antiretroviral agents was a source of stress (Martinez, Lemos, Hosek, & Adolescent Medicine Trials, 2012). The perception of overweight/obesity as being protective for PLWH found in our South Texas study may be the logical consequence of fears of AIDS-related wasting and lipodystrophy previously identified in PLWH, but also represents a significant barrier to weight loss in this population.

This study is the first to explore perceptions of weight loss for PLWH amongst HIV care providers, and identifies several barriers to intervention. Providers express the belief that weight loss intervention is ineffective and that weight loss should be investigated as potentially AIDS or opportunistic infection-related. Providers also noted patients' lack of motivation for lifestyle change and their desire for a quick fix, aligning with perceptions expressed by Latinx youth (Barroso et al., 2010). Another barrier noted by providers, that there was not time during the clinical encounter for lifestyle or weight loss intervention, a perspective shared by primary care providers in other contexts (Simon & Lahiri, 2018). These findings suggest that increasing provider knowledge regarding the need for effective lifestyle interventions for overweight or obese PLWH and expanding resources for referral to

interventions within the clinic are essential components to address HIV/obesity comorbidity in Hispanic PLWH in South Texas.

Despite these barriers, models for successful weight loss and lifestyle intervention exist for both PLWH and Hispanic populations, though no interventions have been targeted to Hispanics living with HIV. For PLWH, data are mixed, with one study demonstrating a lack of impact of lifestyle modification on metabolic syndrome and obesity for PLWH,(Fitch et al., 2012) and others showing reduced fat burden after strength training for men living with HIV with lipodystrophy (Lindegaard et al., 2008; Troseid et al., 2014). Cognitive behavioral therapy was effective for improving body image and self-care in sexual minority men living with HIV, but was not specifically used for weight loss (Blashill et al., 2017). Finally, a small randomized controlled trial of a behavioral weight loss intervention in 40 mostly white non-Hispanic overweight/obese PLWH showed encouraging results, with significantly greater weight loss and improvements in overall health in the intervention group (Becofsky, Wing, McCaffery, Boudreau, & Wing, 2017). Data from weight loss interventions targeted to Mexican American populations suggest that tailoring interventions to incorporate principles of collectivism/familism and community engagement are important (Lindberg, Stevens, & Halperin, 2013; Sorkin et al., 2013; Sorkin et al., 2014). Considering the complex intersection of HIV-specific factors and cultural influences described by Hispanics living with HIV in South Texas, a theoretical model such as the PEN-3 cultural model, which addresses the impact of culture on health behaviors, may be more appropriate for designing interventions for this population (Iwelunmor, Newsome, & Airhihenbuwa, 2014). Our findings may also be relevant to other underserved populations with comorbid illness. For example, perceptions of weight loss, the dominant food culture of South Texas, and the connection between food and family may be relevant for the design of lifestyle interventions for Hispanic populations with diabetes, hypertension, or renal failure (Marquez et al., 2016; Parra-Medina et al., 2015).

There are several limitations to this study. The study's qualitative nature means that interpretation of participants' responses may be biased by the investigators' opinions. Consensual discussion and iterative review of the transcripts and codes, as dictated by grounded theory,(Iman & Manizeh, 2008) helped mitigate this potential bias. Our study focused exclusively on English-speaking Hispanics with HIV in South Texas, a predominately acculturated Mexican American population previously shown to be at high risk for overweight and obesity, and experiencing rapid weight gain over time (Taylor et al., 2014). As such, these findings may not apply to other Hispanic sub-populations, including Spanish-speaking populations. Exploration of similarities or differences in body image and weight perceptions in these groups or in other racial or ethnic minority groups was beyond the scope of this study. Though we considered the role of the race/ethnicity of the provider and the sexual orientation of the patient in our exploratory analysis, we did not find significant differences in themes between these groups. Further explorations of these intersections, possibly with more targeted patient/provider dyad sampling and refinement of the interview guide to focus on these topics, may uncover associations not seen in this investigation.

## CONCLUSIONS

With global obesity rates on the rise, and the intersection of the HIV and obesity epidemics in minority populations, obesity will be a growing health burden for people with HIV in the 21st century. Cardiovascular disease is already a major contributor to morbidity and mortality amongst PLWH, and its importance will increase with the aging of those with HIV (Islam et al., 2012; Sackoff et al., 2006; Triant, 2012; Triant et al., 2007). Obesity and obesity-related complications, such as metabolic syndrome, hypertension, hypercholesterolemia and diabetes mellitus all represent potentially modifiable cardiovascular risk factors for those with HIV. Our data suggest that interventions in Hispanics in South Texas living with HIV must be tailored to address the following: lack of self-efficacy, overweight/obesity as a normative value, cultural beliefs surrounding food and family, fear of HIV-associated weight loss and its accompanying stigma, and provider perspectives on the futility of weight loss intervention. Our findings provide a road map for the design of effective weight loss and lifestyle interventions within this vulnerable population.

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**Table 1.**

Patient participant demographics. Purposive sampling was conducted to ensure representation within BMI categories and by sexual orientation.

| | | Percentage of cohort (Number of participants) |
|---|---|---|
| **Self-identified sexual orientation** | | **N=22** |
| | Heterosexual men | 22.7% (5) |
| | Heterosexual women | 36.3% (8) |
| | Men who have sex with men (MSM) | 40.9% (9) |
| **Birthplace** | | |
| | Continental United States | 91.0% (20) |
| | Puerto Rico | 4.5% (1) |
| | Mexico | 4.5% (1) |
| **BMI** | | |
| | Normal (18.5–24.9 kg/m$^2$) | 31.8% (7) |
| | Over-weight (25–29.9 kg/m$^2$) | 27.2% (6) |
| | Obese (>30.0 kg/m$^2$) | 40.9% (9) |
| | Men – Median BMI | 26.9 kg/m$^2$ |
| | Women – Median BMI | 30.5 kg/m$^2$ |
| **Insurance status** | | |
| | Uninsured | 18.1% (4) |
| | Private/Medicare/Medicaid | 81.8% (18) |
| **HIV infection control** | | |
| | CD4 Count <200 cells/μL | 9.0% (2) |
| | CD4 Count >200 cells/μL | 86.3% (19) |
| | Viral load <20 copies/mL | 72.7% (16) |
| | Viral load >1000 | 18.1% (4) |
| | No viral load available | 4.5% (1) |
| **Diabetes Mellitus (DM)** | | |
| | DM | 27.2% (6) |
| | Obese + DM | 13.6% (3) |
| **Tobacco Use** | | |
| | None | 40.9% (9) |
| | Current use | 45.4% (10) |
| | Quit | 13.6% (3) |
| **Employment** | | |
| | Currently employed | 50.0% (11) |
| | Unemployed / disabled | 50.0% (11) |
| **Relationship Status** | | |
| | Married / committed | 45.4% (10) |

| | | Percentage of cohort (Number of participants) |
|---|---|---|
| | Single | 54.5% (12) |
| **Children** | | |
| | Yes | 40.9% (9) |
| | No | 59.1% (13) |
| **Social Media Use** | | |
| | Facebook / social media use | 45.4% (10) |
| | No online profiles | 54.5% (12) |

**Table 2.**

Stunkard silhouettes. Median responses by weight category for current and goal body habitus. Silhouettes 1–4 correlate with a normal BMI, silhouettes 4–6 with overweight BMI and silhouettes 6–9 with an obese BMI, with overlap between categories as seen in validation study (Kaufer-Horwitz et al., 2006).

| | **Current silhouette #** | **Goal silhouette #** |
|---|---|---|
| Obese BMI (n=9) | 6.5 | 4 |
| Over-weight BMI (n=6) | 5.3 | 4 |
| Normal BMI (n=7) | 5 | 4 |
| **Overall median** | **5.3** | **4** |

**Table 3.**

Themes from interviews about obesity, body image, and healthy lifestyles with Hispanics living with HIV in South Texas.

| Theme | Representative Quotes | Interpretation |
|---|---|---|
| **Non-HIV specific** | | |
| **Dominant food culture** | *I know there's healthy Mexican food somewhere. But um, for the most part…it's just the food. It's all the tortillas.*<br>*It's like a cultural thing. It's absolutely true um, you know. In San Antonio you can find tacos anywhere.* | • Cultural foods are obesity-inducing and cannot be changed<br>• Unlimited access to unhealthy foods |
| **Food and family** | *You're going to make enough in case someone knocks on the door, and they also have enough food to offer to someone else.*<br>*'Are you coming over?' [My family has] so much food. That's how they show that they care about each other.* | • Culture of large family gatherings with excess food showing generosity, community<br>• Food equated to familial love |
| **Obesity as community norm** | *It's just kind of a cycle. You know, your parents are raised that way, and they don't do anything to kind of change it.*<br>*I think that a lot of people have seen themselves like their parents and their uncles. Or whoever have diabetes. So it's kind of like. Instead of thinking, what can I do to not have it, they kind of feel like they're going to get it.* | • Obesity and diabetes are community norms and inevitable |
| **Childhood food access** | *My up bring was never any fruits or vegetables, because I pretty much.*<br>*Or healthy eating. I'd pretty much learned that on my own.*<br>*[as children] …we would eat once in a day.*<br>*I wouldn't fit into clothes for my age. So yeah, I was always aware of that.* | • Unhealthy habits from childhood must be overcome, self-taught healthy eating<br>• Food insecurity as children led to overeating when food is available<br>• Childhood obesity carrying into adulthood |
| **Knowledge base** | On portion size: *"They say, if it fills in your hand or something."*<br>On salads: *"I tried eating like more salads and stuff, but then I just end up hungry all the time."* | • Most participants had clear understanding of portion sizes<br>• Some equated healthy eating to a bland or boring diet |
| **Work environment** | *You know they are working all the time. Parents are just working all the time.*<br>*It's just snacking, cause, there's no time to leave to go get food or anything like that, because I'm stuck at work*<br>*A lot of [drug] reps go into the office … I realize that's just a decision on my part, whether I'm actually going to partake in the food … because it's never anything healthy.* | • Working long hours does not leave time for healthy food prep<br>• Work environment leads to snacking |
| **Cost of healthy food** | *If you look at it now, it's expensive to eat healthy.* | • Cost prohibits healthy eating for low income families |
| **Lack of time** | *I really don't have time to like set up and prepare a whole meal.*<br>*It's more fast food places, because I'm always in a rush. I need to get in and out.* | • Healthy eating and dieting require time for meal prep |
| **HIV-specific** | | |
| **Thin = ill** | *When I left the hospital, I weighed 89lbs. So I looked terrible. Then after 6 months, finally I started bouncing back. Little by little. And ever since then I just ah, obsessed with gaining weight.*<br>*Because when I get Histoplasmosis, I get my, my bones was to the skin…. Because I seen myself as skinny, and I don't want to be skinny any more… Not as skinny, but like sick skinny. No, that's why I always prefer to have a little weight.*<br>*Just my mentality I guess… I just think that if I'm losing weight, I'm getting sick. Even though I'm taking all my medications, like I'm supposed to and everything.*<br>*I'm afraid of not be hungry, because that's the way I get sick. I stop getting hungry. And I start losing [weight].* | • Thinness and weight loss is associated with illness, particularly HIV-related wasting, and therefore negative.<br>• Being overweight looks healthier |
| **Weight as a buffer against future illness** | *I guess because of my HIV. And, you know I'm going to end up in the hospital again, or something like that. So that's why, you know what I mean. I start to try to eat more, and more. You know what I mean? … It's just like something you know, when you go through something, and experience like that. 46 days on the bed you know. And you're bone skinny.*<br>*I was thinking, you know the bigger, on, on my sickness. You know, the bigger … You know, the more nutrition I get... More protein I get … It'll do better to my sickness.* | • Being overweight is protective if you are likely to get sick again |

| Theme | Representative Quotes | Interpretation |
|---|---|---|
| **Weight hides HIV-related body changes** | *My cheeks got sucked in and I know that's part of the HIV and stuff. But you can never see. You can never tell on me, but when, when I'm that thin you sure can.*<br>*It was a combination, because my cheeks got sucked in and I know that's part of the HIV and stuff…that's such and ugly look.*<br>*I read in the articles when you get…HIV, you get like a gut stomach.* | • Increased weight hides lipodystrophy (or other HIV-related body changes) |

**Table 4.**

Themes from interviews with providers about patient's perceptions of obesity, body image, and healthy lifestyles with Hispanics living with HIV in South Texas.

| Theme | Representative Quotes | Interpretation |
|---|---|---|
| **Barriers to intervention for provider participants** | | |
| **Counseling as ineffective** | *"I think the general approach is, how many battles am I choosing today?"*<br>On effective counseling methods: *"My cynical side is tempted to say nothing. But I think maybe recognizing somebody who is actually motivated to change… I think what works best is internal motivation."*<br>*"The sample size of those patients who have tried to lose … is relatively small. I can probably count them on one hand."* | • Fatalistic attitude towards obesity counseling<br>• Ineffective counseling |
| **Patients not motivated to change** | *"My perception is that they are not as concerned about their weight as I am."*<br>*"I think a majority of patients are not motivated to lose weight."*<br>*"I think what they want is, can I identify a lab, can I identify some treatment…but you're only going to lose weight if you eat less calories."* | • Patients lack concern, motivation and hope for quick fixes or underlying causes for obesity |
| **Negative reactions to weight loss** | *"I had one lady that lost 15 pounds and it seemed stress related. But she was still obese and concerned that she was too skinny."*<br>*"I would inquire about whether or not they've been sick…to try and figure out whether or not there is something, if they have not been trying to intentionally lose weight."* | • Regional preference for overweight body habitus<br>• HIV infection prompts different response from providers |