

2015

Body Image Experiences of Racial/Ethnic Minority Heterosexual Males Living with HIV/AIDS: An Interpretative Phenomenological Analysis

Michele Mercedes Vella
Lehigh University

Follow this and additional works at: <http://preserve.lehigh.edu/etd>



Part of the [Counseling Psychology Commons](#)

Recommended Citation

Vella, Michele Mercedes, "Body Image Experiences of Racial/Ethnic Minority Heterosexual Males Living with HIV/AIDS: An Interpretative Phenomenological Analysis" (2015). *Theses and Dissertations*. 2856.
<http://preserve.lehigh.edu/etd/2856>

This Dissertation is brought to you for free and open access by Lehigh Preserve. It has been accepted for inclusion in Theses and Dissertations by an authorized administrator of Lehigh Preserve. For more information, please contact preserve@lehigh.edu.

Body Image Experiences of Racial/Ethnic Minority Heterosexual Males Living with HIV/AIDS:
An Interpretative Phenomenological Analysis

by

Michele M. Vella

Presented to the Graduate and Research Committee of

Lehigh University

in Candidacy for the Degree of

Doctor of Philosophy

in

Counseling Psychology

Lehigh University

April 2015

Copyright by Michele M. Vella

April 2015

Approved and recommended for acceptance as a dissertation in partial fulfillment of the requirements for the degree of Doctor of Philosophy.

Date

Dissertation Advisor: Grace I. L. Caskie, Ph.D.

Accepted Date

Committee Members:

Grace I. L. Caskie, Ph.D.
Associate Professor, Lehigh University

Susan Woodhouse, Ph.D.
Associate Professor, Lehigh University

Christopher Liang, Ph.D.
Associate Professor, Lehigh University

Yuying Tsong, Ph.D.
Assistant Professor, California State University, Fullerton

Acknowledgements

My sincerest thanks to my husband Michael for his enduring love and support; my valued colleagues; my participants for their willingness to share their lives and stories; my advisor Dr. Grace Caskie for her years of dedication and guidance; and the American Psychological Association Minority Fellowship Program for their belief and investment in me, with a special thanks to Director Andrew Austin-Dailey and Dr. Miriam Martinez. This dissertation research was supported by the American Psychological Association Minority Fellowship Program (grant # SM060563).

TABLE OF CONTENTS

List of Tables.....	vi
Abstract.....	1
Chapter I: Introduction.....	2
Study Purpose.....	12
Chapter II: Review of the Literature.....	13
Early Body Image Research.....	13
Men in Body Image Research.....	14
Body Image Research Disparities for Racial/Ethnic Minority Males.....	15
Body Image Research and Sexual Orientation.....	17
Self-Objectification, Body Image, and Heterosexual Males.....	19
Defining Masculinity.....	20
Patterns of Masculinity.....	21
A Misrepresented Image.....	22
Race and Ethnicity Matter.....	23
Chapter III: Research Method.....	40
Researchers.....	40
Interpretative Phenomenological Analysis.....	41
Participants.....	42
Instruments.....	44
Procedure.....	49
Overview of Analysis.....	52
Trustworthiness.....	60
Chapter IV: Results.....	62

Chapter V: Discussion.....	94
Limitations, Strengths, and Conclusion.....	116
Executive Summary.....	122
References.....	125
Appendix 1: Research Recruitment Flyer.....	171
Appendix 2: Semi-Structured Body Image Interview Guide.....	172
Appendix 3: Demographic Questionnaire.....	177
Appendix 4: Body Image Survey.....	179
Appendix 5: Perceived Lipodystrophy Scale.....	182
Appendix 6: Informed Consent Form.....	185
Biography.....	190

List of Tables

Table 1. Demographic characteristics of participants	145
Table 2. Body Image Questionnaire	148
Table 3. Perceived Lipodystrophy Scale (PLS).....	154
Table 4. Master Theme Table.....	157

ABSTRACT

People living with HIV or as AIDS defined (PLWHA) may experience significant physical and metabolic alterations (i.e., lipodystrophy syndrome) as a side effect of HIV medications (i.e., Highly Active Antiretroviral Therapy) leading to profound transformations in body image (Collins et al., 2000). Despite the significant percentage of racial/ethnic minority heterosexual men living with HIV or as AIDS defined (REHMHA) both in the United States and globally and the known adverse effects of HAART on the body, the body image experiences of REHMHA have been unaccounted for in quantitative or qualitative research. The present study conducted in-depth semi-structured interviews with 21 REHMHA using open-ended questions and prompts conceptualized according to three domains thought to be important to body image—the perceptual, the behavioral, and the subjective (Thompson, 1990). In addition, the participants filled out a demographic questionnaire, body image questionnaire, and Perception of Lipodystrophy Scale (PLS). Ninety-five percent of participants reported perceived lipodystrophic alterations on the PLS with fat accumulation in the abdomen and face. Analysis of semi-structured interviews was conducted using interpretative phenomenological analysis (IPA). IPA revealed three super-ordinate themes or main areas of concern to REHMHA’s understanding of body image— “describing the valued and devalued body;” “losing and gaining control” and “navigating social dimensions of visibility and invisibility.” The results suggest that intrapersonal, interpersonal, and social experience of HIV or AIDS defined status and HAART-related physical transformations are important aspects of how REHMHA understand and explore their body images.

Chapter I

Introduction

In order to survive, individuals living with the human immunodeficiency virus infection/acquired immunodeficiency virus (HIV/AIDS) must adhere to medications that dramatically and irreversibly transform their bodies —Highly Active Antiretroviral Therapy (HAART) (Steel, Landsittel, Calhoun, Wieand, & Kingsley, 2006). By reducing HIV viral load, boosting immune system functioning, and extending life expectancy, HAART redefined HIV from a death sentence to a complex chronic disease (Reynolds, Neidig, Wu, Gifford, & Holmes, 2006). However, despite HAART's promise of additional years of life, it may also subtract years of life enjoyed as the individual may look in the mirror and no longer recognize his or her reflection (Gagnon & Holmes, 2008). HIV affects the body biologically, psychologically, and socially (Chapman, 1998). Thus, HIV and the medication used to treat HIV should not be conceptualized solely through the lens of biomedical/scientific understanding (Persson, 2004). Rather, they should be thought of as lived experience, embodied both personally and relationally (Bowleg, 2012; Persson, 2004).

Given that heterosexual sex is the HIV transmission risk factor for more than 70% of HIV infections worldwide and that HAART is necessary for survival, the voices of HIV positive men identifying as heterosexual should be included in body image research on HIV (Dworkin, Fullilove, & Peacock, 2009). Yet, the qualitative body image experiences of heterosexual men living with HIV, particularly heterosexual HIV positive racial/ethnic minority males, have been virtually ignored in scientific research (Collins, Wagner, & Walmsley, 2000; Sharma et al., 2007). Thompson (1990) posited that three intersecting domains construct a person's sense of body image --- the perceptual (e.g., self/internal and social/external sense of the body's shape

and size); the behavioral (e.g., changing behaviors to amend body dissatisfaction or behavioral changes as a reaction to psychological distress); and the subjective (e.g., social investments attached to the body). Thus, the current study explores the body image experiences of males living with HIV or AIDS, identifying as heterosexual and a racial/ethnic minority, and who are currently taking or having a history of taking HAART and uses Thompson's three domains as a starting point to discuss the lived experiences of body image in this population.

HAART may create significant metabolic and deforming physical/bodily alterations known as lipodystrophy syndrome (Reynolds et al., 2006). Lipodystrophy syndrome embodies patterns of bodily fat redistribution that include body fat gain (i.e., lipohyperatrophy), body fat loss (i.e., lipoatrophy), or a mixture of body fat gain and loss (Bonnet, 2010). Examples of lipodystrophic changes include fat accumulation in the back (clinically referred to as buffalo hump); heavy fat deposits leading to enlarged breasts; fat sedimentation in the mid-abdomen giving the appearance of a mid to late trimester pregnancy; fat wasting in the buttocks, arms, legs, and face; and bulging veins as a result of subcutaneous fat loss (Collins et al., 2000). Other health complications may manifest as a result of lipodystrophy syndrome including cardiovascular disease, type 2 diabetes, high cholesterol, and osteoporosis (Carr, 2012).

A significant gap in understanding may exist between how the HIV positive individual experiences lipodystrophy syndrome and how the medical provider/researcher conceptualizes lipodystrophy syndrome (Gagnon & Holmes, 2008). In asking heterosexual HIV positive women and gay HIV positive male research participants to speak about their bodies, Collins et al. (2000) noted the descriptors "grotesque," "deformed," "damaged goods" and "weird looking" (p. 547). Persons living with HIV may be willing to sacrifice 10-15% of their life expectancy in exchange for a body without lipodystrophy syndrome (Gagnon & Holmes, 2008). Research

indicates that lipodystrophy may affect more than 60% of HIV positive individuals (Carr, 2012), with estimates reaching as high as 84% (Tien & Grunfield, 2004), yet the medical provider/researcher still has no “standard objective case definition” of lipodystrophy syndrome (Sax, 2012, p. 8). Carr et al. (2003) attempted to create an objective model definition of lipodystrophy for use in research. However, of the 417 participants used for the Carr et al. model, 343 (83%) of participants were males, 323 (78%) identified as White, and 273 (65%) identified their HIV risk exposure category as “homosexual” sex (Carr et al., 2003, p. 4). Thus, this model of lipodystrophy does not represent the full spectrum of experiences including females, racial/ethnic minority individuals, and other HIV risk exposure categories including injection drug use and heterosexual sex.

Although ample research exists on the body image experiences of non-HIV positive heterosexual individuals who are racially or ethnically classified as White or Caucasian (e.g., Leit, Gray, & Pope, 2002), heterosexuals with other chronic diseases (e.g., Hopwood, Fletcher, & Ghazal, 2000), and HIV positive males identifying as gay, homosexual, or men who have sex with men (MSM) (e.g., Collins et al., 2000; Huang et al., 2006b; Tate & George, 2001; Varas-Diaz, Toro-Alfonso, & Serrano-Garcia, 2005), there is a paucity of body image research on heterosexual men infected with HIV. This is a significant research gap given that more than 70% of HIV infections globally are transmitted through heterosexual sex (Dworkin et al., 2009).

In the United States, heterosexual sex accounts for 31% of new HIV transmissions and 28% of all individuals living with HIV (CDC, 2010). Of these cases, the majority of new infections are amongst individuals classified as racial and ethnic minorities including Black (82%) and Latino (85%) (KFF, 2013). Black males are six times more likely to be infected with HIV than their White male counterparts (Higgins, Hoffman, & Dworkin, 2010). Latino males

are twice as likely to be infected with HIV than their White male counterparts (Higgins et al., 2010). An overview of the demographic characteristics of this cohort depicts a portrait of extreme health disparities. Heterosexual individuals living in poverty and in urban enclaves are five times more likely to be HIV positive than heterosexuals living in the same urban region but of higher socioeconomic status (Human Rights Watch, 2011). Individuals identifying as Black constitute 13% of the U.S. population but 46% of persons living with HIV/AIDS (Human Rights Watch, 2011). Seventy percent of individuals identifying as Black and living with HIV/AIDS are males (CDC, 2014).

For Black men, transmission risk varies by U.S. region and even state. For example, in the Northeastern region of the United States (e.g., Maryland, Pennsylvania, Washington DC), heterosexual sexual transmission of HIV poses the greatest transmission risk for Black men (Raj & Bowleg, 2012). In contrast, men having sex with men (MSM) is the greatest transmission risk for Black men nationwide. In states with limited access to medical care, high rates of poverty, insufficient housing, and minimal transportation, racial/ethnic minority individuals suffer the greatest inequities in HIV care (Human Rights Watch, 2011). Over half of the individuals living with HIV or AIDS in Mississippi will not receive crucial and lifesaving treatment, a rate similar to Botswana, Rwanda, and Ethiopia (Human Rights Watch, 2011).

Men identifying as heterosexual and Latino do not fare much better than their Black male counterparts for HIV transmission exposure (Bowleg, 2011b). The most frequent mode of HIV transmission after injection drug use (39%) in Puerto Rico, a Commonwealth of the U.S., is heterosexual sexual contact (37%) (CDC, 2009). It should be noted that the Caribbean has the second highest rate of HIV/AIDS infection in the world after Sub-Saharan Africa (United Nations Joint Program on AIDS, 2009). Puerto Rico is considered both part of the United States

and a geographic constituent of the Caribbean. Travel from Puerto Rico to the United States is relatively easy as Puerto Ricans are considered U.S. citizens with affordable travel access to mainland U.S. locations.

Outside of Puerto Rico, 17% of Latino males newly infected with HIV cited heterosexual transmission risk (Bowleg, 2011b). In comparison to Black and Latino HIV positive males, only 11% of HIV positive White males in three decades attributed their infection to heterosexual transmission (Bowleg, 2011b). It should be highlighted that these statistics do not necessarily account for sexual orientation identification as epidemiological data on HIV/AIDS identifies individuals according to HIV sexual transmission risk category and not by sexual orientation (Roth & Hogan, 1998).

Yet, not acknowledging this heterosexual orientation identification may significantly influence HIV prevention, intervention, and treatment strategies (Adimora & Schoenbach, 2002). In a review of HIV prevention intervention for heterosexual males, Elwy, Hart, Hawkes, and Petticrew (2002) found only 12 published studies. The majority of these studies focused on injection drug use rather than heterosexual sex as a risk factor for heterosexual males (Elwy et al., 2002; Seal & Ehrhardt, 2004). According to CDC HIV/AIDS reporting guidelines, if a man identifies multiple risk factors for HIV transmission (e.g., injection drug use and heterosexual sex), he is categorized by the other risk factor (e.g., injection drug use) instead of heterosexual sex (Seal & Ehrhardt, 2004). This categorization as an injection drug user ignores the fact that he engages in heterosexual sex and may even have contracted HIV through heterosexual sex and not injection drug use (Seal & Ehrhardt, 2004). In a sense, his identity as a heterosexual male goes unaccounted for as it may be simultaneously legitimized and illegitimized.

The HIV transmission risk factor of men having sex with men (MSM) may also obscure identification with heterosexual sexual orientation. Specifically, men may engage in sexual intercourse with other men but identify with a heterosexual sexual orientation. Wohl et al. (2002) found that 47% of Black men ($N = 362$) reported having anal intercourse with other men but still identified with a heterosexual sexual orientation. In addition, 53% of the Black men in the Wohl et al. study identified as having penile/vaginal intercourse with a woman and having a heterosexual sexual orientation. The latest CDC transmission risk data (2010) reveals that almost one-third of HIV infected individuals do not report their HIV risk transmission category, with Black males comprising the largest percentage of all men to endorse the HIV transmission risk category of “other risk factor not reported or identified.” To ignore sexual orientation identification, however, may overlook an integral part of the way HIV is embodied, managed, and lived in HIV positive males of all sexual orientations.

Despite the fact that body image is known to have a negative impact on multiple life dimensions of an individual living with HIV or AIDS, heterosexually identified racial and ethnic minority males are not included HIV body image research. Existent HIV research literature has documented multiple facets of how the HIV positive body may be adversely experienced. Lower physical self-perceptions may be related to a decrease in sexual activity (Turner, 1995). A poor sense of body image may contribute negatively to self-esteem, doctor-patient relationships, and medical compliance, and may increase depression (Collins et al., 2000). It may affect overall health, physical functioning, pain, mental health, substance use/abuse, health distress, quality of life, and total health status scores (Corless, Nicholas, McGibbon, & Wilson, 2004) and may indicate HIV status to the community or contribute to self-stigmatization (Varas-Diaz et al., 2005).

HIV positive individuals have felt that medical providers discount and minimize their expressed body image concerns (Collins et al., 2000; Gagnon & Holmes, 2011). With the advent of HAART, providers equated an undetectable HIV viral load on laboratory blood work results as the hallmark of treatment success (Persson, 2004). This medical definition of success, however, negates the lived experience of HAART as it may transform the individual and social interpretations/meanings attached to the HIV positive body (Persson, 2004; Tate & George, 2001).

In a qualitative study on the effects of body image and HIV positive related weight loss in gay men classified as White and living in England ($N = 8$), Tate and George (2001) noted that body image may be especially complex for the HIV positive individual. They used the body image framework of Thompson (1990) to contextualize the dynamic transformations of the HIV positive body. All three domains of Thompson, the perceptual (e.g., self/internal and social/external sense of the body's shape and size); the behavioral (e.g., changing behaviors to amend body dissatisfaction or behavioral changes as a reaction to psychological distress); and the subjective (e.g., social investments attached to the body) may undergo complete transformation by lipodystrophy syndrome (Martinez, Kemper, Diamond, Wagner, & the California Collaborative Treatment Group, 2005).

Lipodystrophy may affect the perceptual domain or a person's sense of her/his body shape and size and consequently self-perceived body image (Martinez et al., 2005; Thompson, 1990). Gagnon and Holmes (2008) point out that bodily perception is subjective and constructed by the self. If a physician does not acknowledge the patient's perspective, then lipodystrophy becomes a side effect instead of a dynamic and lived process (Collins et al., 2000; Persson, 2004). Studying body image and weight loss in a group of eight White HIV positive gay men,

Tate and George (2001) had participants choose from silhouette figures ranging from extremely thin to obese as used by Stunkard, Sorenson, and Schlusinger (1983) to measure size perception accuracy. However, because these silhouette figures were generated from non-HIV positive Danish participant samples (Tate & George, 2001), this perceptual shape size measure may not be appropriate for persons with lipodystrophy as areas of fat wasting and/or fat gain are often times unpredictably distributed on the HIV positive HAART body (Persson, 2005). Further, heterosexual racial/ethnic minorities living with HIV or AIDS may not have the same perceptual ideals of body shape and size as non-HIV positive, gay/MSM/bisexual/lesbian identified, or HIV positive White samples (Demarest & Allen, 2000; Sharma et al., 2007). Given that HIV disproportionately affects racial/ethnic minority individuals (CDC, 2010, 2013), the need for appropriate body image measures is further emphasized.

Body image perception of lipodystrophy may also impact the behavioral domain (Plankey et al., 2009; Thompson, 1990). Individuals report not taking medications because of adverse effects on the body such as weight gain (Sansone, Sansone, Gaither & Morris, 2004). In the HIV positive population, self-perceived fat gain or fat loss has been shown to decrease adherence to HAART or taking HIV medications as prescribed for maximum effectiveness (Ammassari et al., 2002; Duran et al., 2001; Plankey et al., 2009; Santos et al., 2005). Poor adherence to HAART increases HIV virus reproduction, leads to greater health complications, progression to AIDS, and death (Stone, Jordon, Tolson, Miller, & Pillon, 2004). HIV positive individuals may also feel increased depression and anxiety as a result of bodily changes (Collins et al., 2000). She/he may engage in more dieting, exercising rituals, and even wearing different clothing in an attempt to masque distressful bodily changes (Gagnon & Holmes, 2011; Seidl & Machado, 2008).

Lipodystrophy may influence a person's sense of subjective body image or the social value placed on her/his body (Thompson, 1990). The body serves as a form of social capital with a figurative currency generated from society's sense of its utility or inutility (Crawford, 1994). Early public health images of HIV/AIDS wasting (e.g., hollowed cheeks, loss of muscle mass, and weight loss) signified reduction in health status, a body ravaged by disease, and death (Crawford, 1994). Public health images and media-transmitted understandings of HIV may shape subjective body image for HIV positive individuals. From the earliest definition of HIV as a disease belonging to "Haitians, homosexuals, heroin users, and hemophiliacs," HIV infected persons knew that their subjective body image belonged to a marginalized out-group (CDC, 1983). Bodily changes induced by HAART may add to the pejorative collection of descriptors historically used to represent the HIV epidemic including deviant sexuality, moral depravity, and contagion (Crawford, 1994). Permanent external changes marked by earlier physical changes before HAART (i.e., effective treatment regimens) or lipodystrophic changes with HAART created a stigmatized body or social cues and reminders of the subjective body image (Varas-Diaz et al., 2005). Branded by permanent external changes, lipodystrophy threatens to reveal HIV positive status without the individual's consent (Persson, 2005). The body image experiences of HIV positive or AIDS defining heterosexual men, specifically racial/ethnic minority HIV positive or AIDS defining heterosexual men, are non-existent in qualitative and quantitative research. Even in the quantitative research of Huang et al. (2006a) on HIV positive male body image, all participants not identifying as MSM are collapsed into a sexual orientation category of "other". This pronounced absence of heterosexual HIV positive men in research parallels the absence of heterosexual HIV positive men in the Center for Disease Control and Prevention's representation of male populations infected with HIV and HIV risk

reduction//prevention/intervention campaigns (Bowleg, 2011b; Exner, Gardos, Seal, & Ehrhardt, 1999; Higgins et al., 2010). Exner et al. (1999) labeled heterosexual men “the forgotten group” of HIV positive research (p. 347).

The body image experiences of men identified as MSM, homosexual, and gay HIV positive males account for all of the research on HIV positive male body image. In a meta-analytic review of differences in body image satisfaction between self-identified gay and heterosexual men and lesbian and heterosexual women ($N = 5220$), Morrison, Morrison, and Sager (2004) found that, overall, gay men appear to be only slightly more vulnerable to body dissatisfaction than heterosexual males. Research suggests that United States culture tends to value a muscular physique as the ideal male body type (Leit et al., 2002). This ideal male muscular body type has been documented in research on the evolution of children’s action toys (Pope, Olivardia, Gruber, & Borowiecki, 1998) and an examination of body type in over 25 years of Playgirl centerfolds (Leit, Pope, & Gray, 2000). As lipodystrophy syndrome is known to simultaneously reduce and increase fat, a HIV positive male with a flat buttock, pot belly appearance, and facial wasting may not match this ideal of musculature.

Qualitative research has the ability to capture the voices of disparate and marginalized populations (Bowleg, 2011a). In the over 30 years of HIV/AIDS research, qualitative methodology has helped illuminate the experience of HIV/AIDS at it is lived by the individual. Qualitative research strategies may serve as a vehicle for the HIV positive heterosexual community to create a more equitable representation of body image transformed by HAART — shifting the dialogue from the purely biomedical (i.e., defined by the doctor/medical researcher) to the personal (Gagnon & Holmes, 2008, 2011). Yeh and Inman (2007) noted that qualitative research is congruent with counseling psychology’s emphasis on self-reflection and

multiculturalism. Additionally, qualitative research allows for an interdisciplinary application which may be of particular importance to studying HIV, an epidemic necessitating the crossing of multiple disciplines including medicine, psychology, psychiatry, public health, sociology, anthropology, and education (Yeh & Inman, 2007).

Study Purpose

The purpose of this study is to qualitatively explore the body image experiences of HIV positive males who self-identify as heterosexual, racial/ethnic minorities, and are currently taking or having a history of taking HAART (hereafter referred to as REHMHA). This study will enable a marginalized population's voice (e.g., REHMHA) to be taken out of the margins and to contribute to the body image research of multiple disciplines (e.g., HIV/AIDS, infectious disease, patient care, health disparities, racial/ethnic minority health, public health, and counseling psychology). It will use an interpretative phenomenological analysis (IPA) approach (Smith, Flowers, & Larkin, 2013), an approach centered in psychology and used in clinical, counseling, social, and educational psychology, and cited for its focus on the lived meanings, understandings, and perceptions of individuals as they undergo a specific process or phenomena (Smith et al., 2013). Generating initial interview questions broadly from the body image framework of Thompson (i.e., the perceptual, the behavioral, and the subjective domains constituting facets of body image), this study seeks to explore how REHMHA understand their body image after taking combination antiretroviral medications (HAART) to treat HIV or AIDS.

Chapter II

Review of the Literature

Early Body Image Research

The evolution of body image research shows the complex, diverse, and multi-dimensional nature of understanding and defining body image. One of the first studies on the long term physical and psychological effects of induced starvation, essentially what is called anorexia nervosa, was performed on a group of young males (Keys et al., 1950). Thirty-six young men identified as White and deemed psychological and physically healthy participated in this study in lieu of military service. The study lasted for a total of nine months with three phases of imposed starvation, a decrease in extreme food restriction, and then a re-feeding phase (Keys et al., 1950). Participants expressed depression, engaged in food hoarding behaviors, and voiced distress about their body images including “feeling fat” and how they regained fat in several areas of their body including the “abdomen and buttocks” (Keys et al., 1950, p. 828).

Other early studies focused on body image as interpreted by the field of neurology (Thompson, 1990). These include the impact of cortical functioning on experiences of limb dissociation or feeling as if one should not have a limb (Gerstmann, 1958) and the persistence of feeling of a limb post amputation (Murray Parkes, 1973). In the field of psychology, definitions of body image rapidly expanded to incorporate theoretical frameworks from psychoanalytic theory to explain compensatory masculinity in male body building (Harlow, 1951), developmental theory in changing attitudes about body pre and post puberty (Gunn & Warren, 1985), socio-cultural theory to examine standards of body beauty and disordered eating (Striegel-Moore, Silberstein, & Rodin, 1986), cognitive theory of disturbed body schemas (Kearney-

Cooke & Striegel-Moore, 1997), and health theories describing body transformations of disease processes such as cancer (Hopwood, Fletcher, Lee, & Al Ghazal, 2001).

Men in Body Image Research

Several decades after studies like the Keys et al. (1950) study, body image researchers revisited male specific body image inquiries/considerations (Cafri et al., 2005). In order to achieve their ideal physique, men reported that they would need to add 28 pounds of muscle mass to their bodies (Pope et al., 2000). Specifically, men would like to add this muscle mass to pectorals, biceps, and shoulders (McCreary, Saucier, & Courtenay, 2005). Men have expressed similar rates of body dissatisfaction as females (Olivardia, Pope, Mangweth, & Hudson, 1995). Male body dissatisfaction may manifest from failure to achieve a cultural expectation of hyper-muscularity (Leit et al., 2000; Pope, Phillips, & Olivardia, 2001). These physical ideals are transmitted through mediums such as magazines, advertising, and television (Leit et al., 2000). Gender role socialization can occur through a variety of covert and overt sources. For example, social messages, familial expectation of gendered behavior, concrete representations of masculine physical ideals (e.g., male action toy figures) can all represent varying forms of gender socialization (Leit et al., 2002; Pope et al., 1998; Schwartz, Grammas, Sutherland, Siffert, & Bush-King, 2010).

Just as a thin ideal may lead to female anorexia or bulimia, expectations of building an unrealistic male muscular physique can result in muscle dysmorphia (MD) (Boisvert & Harrell, 2012). MD encompasses attitudes and beliefs about muscular inadequacy (McCreary, Hildebrandt, Heinberg, Boroughs, & Thompson, 2007). Men suffering from MD may feel chronic distress that interferes with daily functioning accompanied by symptoms of depression and anxiety (McCreary et al, 2007). In an attempt to achieve a muscular ideal, men with MD

may also engage in risky compulsive behavior such as extreme dieting to lose or gain weight; bingeing and purging; excessive weight lifting; use of anabolic steroids (McCreary et al., 2007); use of pro-hormones that are chemically similar to anabolic steroids (Cafri et al., 2005); use of the stimulant ephedrine (Cafri et al., 2005); ingestion of large quantities of nutritional supplements such as powdered protein (Blouin & Goldfield, 1995; Boisvert & Harrell, 2012). Shaving or trimming of body hair, also known as body depilation, may be used in an attempt to accent muscle shape/size (McCreary et al., 2007).

Body Image Research Disparities for Racial/Ethnic Minority Males

Comparatively more information is available regarding how racial and ethnic identification contributes to body image for females than for males (Boisvert & Harrell, 2012). Several studies found that Asian women have less body dissatisfaction than White women (Akan & Grilo, 1995; Cachelin, Rebeck, Chung, & Pelayo, 2002). After controlling for age, SES, and BMI in a community sample of women ($N = 801$), Cachelin et al. (2002) reported similar levels of body dissatisfaction for Black, White, and Hispanic women. However, other studies have noted that Hispanic women have greater body dissatisfaction and disordered eating patterns than White and Asian American women (Boisvert & Harrell, 2012). Despite the presence of disordered eating symptoms, Becker, Franko, Speck, and Herzog (2002) found that women who identified as Latino or Native American were less likely to be referred for subsequent care.

Scant research exists on body image for racial/ethnic minority males (Cachelin et al., 2002; Feldman & Meyer, 2007). It is possible that body image research does not exist for racial/ethnic minority males because of the exclusion of women and racial ethnic minorities in studies funded by the National Institute of Health (NIH) (IOM, 2012). It should be noted that not until 1993 did the NIH mandate the inclusion of women and minorities in NIH research with

the NIH Revitalization Act of 1993 (IOM, 2012). Although many body image studies may not have been funded by the NIH or fall under the category of clinical research, researchers may still have replicated a research norm whereby homogenous White males made up the samples of all clinical research studies (IOM, 2012). When racial/ethnic minority males started to gain inclusion in body image research studies, body image researchers may not have been aware of the degree of their own blind spots, biases, and assumptions. In a study on gender, ethnicity, and age differences in body image, African American, White, and Hispanic men asserted that females would prefer “bulkier” male body shape (Demarest & Allen, 2000, p.469). This result does not necessarily indicate what male participants would prefer for their own bodies. Regardless of categorized ethnicity, the males in this study reported satisfaction with their bodies (Demarest & Allen, 2000).

Certain male racial/ethnic categories may express body image dissatisfaction related to muscle mass. Schwartz et al. (2010) found that being categorized as Asian American was a significant positive predictor of muscle dissatisfaction. Asian American participants also demonstrated a “lack of clear sense of self” and “emotional enmeshment” that the researchers related to high body image concerns (Schwartz et al., 2010, p. 208). This conclusion remains questionable given that participants from collectivistic cultures may not value autonomy and/or community over self. Further, because this study examined body image in college male participants, other factors may have contributed to high body image concerns such as socio-economic status, college life transitioning, home sickness, food choice, decreased exercise at college, increased study time, or sub-group ethnic identification.

Body Image Research and Sexual Orientation

Research is not conclusive on the role that sexual orientation identification plays in body image. Studies have shown that men identified as gay men have greater body image concerns, higher rates of body dissatisfaction, and an increased chance of developing eating disorders than men identified as heterosexual men (Hospers & Jansen, 2005; Russell & Keel, 2002; Strong, Sing, & Randall, 2000). Although some studies indicate that gay identified men place a greater value on musculature and heterosexual identified men value thinness (Kaminski, Chapman, Haynes, & Own, 2005), other studies posit that gay and heterosexual identified men share equal desires to be thin and muscular (Martins, Tiggerman, & Kirkbride, 2007). A meta-analytic review of 27 studies on sexual orientation with a total of 2381 male participants (heterosexual men = 1397, gay men = 984) reported only a slight difference in body satisfaction for heterosexual men and gay men (Morrison et al., 2004). Age variations of included participants varied widely with an average age of 18.8 to 30.1 years (Morrison et al., 2004). Race and/or ethnicity of participants in this meta-analytic review were not accounted for.

Some body image studies describe male body image disturbance as being synonymous with male gay sexual orientation and feminine trait orientation. On closer examination, this explanation may be a leftover vestige of psychoanalytic theory. Harlow (1950) isolated variables from two projective test measurements, the Thematic Apperception Test and the Sentence Completion Test, to compare psychoanalytic trait concepts in an experimental group of weight lifters ($n = 20$) and a control group of non-weightlifting athletes. It was hypothesized that weightlifting men mask their “latent homosexual impulses” and proclivity towards feminine traits through a hyper-muscular physique (Harlow, 1950, p. 315). Harlow confirmed his hypothesis as the exploratory group of weight lifters scored higher than the non-weight lifter

male control group on projective tests for variables that he believed were synonymous with “latent homosexual impulses” and feminine traits including masculine inadequacy, childhood exposure to an insecure environment, inability to identify with male figures such as a father, a high degree of narcissism, and dependency (p. 315). Harlow concluded that weight lifting men physically overcompensated for their true underlying insecurity and feminine trait identification through reshaping their bodies as muscular facades to hide “masculine inadequacy” (p. 317). This early study by Harlow, with its presumption of “homosexual impulses” as necessarily pathological and its association of musculature with feminine traits and of gay male identity with traditional female gendered expectations has had a negative influence on later male body image research (p. 315).

Other psychology researchers extended the exploration of sex roles in male body image terming the muscular exaggeration of male physique “compensatory masculinity” (Babl, 1979, p. 252). Babl (1979) argued that a man socialized to play a traditional masculine role would feel more anxiety and engage in compensatory masculinity whereas an “androgynous male” would be comfortable with both masculine and feminine traits. To test his interpretation of compensatory masculinity, 72 second year males were categorized into a traditional masculine group and an androgynous group. They were measured for sex role with the Bem Sex-Role Inventory (Bem, 1981), the Affect Rating Scale as a measure of anxiety (Sipprelle, Ascough, Detrio, & Horst, 1977), and the California Social Inventory Fe Scale (Gough, 1957) to measure participant fit on a masculine-feminine gendered spectrum. Participants were then exposed to audio-taped recordings as stimulus to induce a threat to masculinity. Participants in the traditional masculine group demonstrated higher levels of masculinity and antisocial behavior. Participants in the

androgynous group demonstrated lower levels of masculinity and more socially desirable behavior.

Together, the Harlow (1950) and the Babl (1979) studies provide a lens to critique male body image research including inherent dominant group stereotypes and rendering pathological/abnormal human behaviors that do not fit into socio-cultural normative behavior. Decades later, the essentialist assumptions of this research resonate. The desire to be both muscular and attractive is synonymous with gay male culture. This reflects Harlow's (1950) understanding of female traits and homosexual tendencies in male weight-lifters. It also parallels Babl's (1979) correlation of lower levels of masculinity and higher levels of conformation to social desirability in the androgynous classified male group. As Morrison et al. (2004) point out, no adequate rationale exists to explain why gay male culture is portrayed as caring more about attractiveness than heterosexual male culture.

Self-Objectification, Body Image, and Heterosexual Males

Self-objectification or “adopting an observer's perspective on physical self” should be extended to examining body image in heterosexual identified males (Martins et al., 2007, p. 634). Objectification theory was first used to explain the body image experiences of females whose bodies served as a vehicle for male pleasure. Eventually the woman who is objectified internalizes the gaze, perceives herself as object instead of human being, and may experience symptoms of psychological distress such as anxiety, depression, and shame (Martins et al., 2007). Objectification theory has been extended to include the experiences of gay males. Gay males who feel objectified report higher rates of body image dissatisfaction and eating disorders (Atkins, 1998). Research has argued that gay culture is objectifying and that gay men internalize this objectification through efforts of achieving a bodily ideal.

Little is known about how heterosexual male culture may experience objectification. Using a paper and web survey to examine self-objectification in gay identified ($n = 57$) and heterosexual identified males ($n = 68$), Martins et al. (2007) found that heterosexual participants did engage in self-objectification. Heterosexual male objectification was related to body dissatisfaction and disordered eating attitudes (Martins et al., 2007). However, this study did not account for the race or ethnicity of participants. Additional variables of racial/ethnic minority status or HIV status may compound the male heterosexual experience of objectification.

Defining Masculinity

Connell (1995) noted the universality of cultural accounts of gender but not masculinity. According to Connell (1995), masculinity is a relatively modern product of European culture, a capitalist economy, colonialism, and a nineteenth century bourgeois ideology of separate spheres for men and women. Prioritizing a European cultural perspective, four strategies became employed to define masculinity including essentialist, positivist, normative, and semiotic approaches. First, an essentialist perspective defines masculinity as a core feature or essence with disagreement about the universal nature or essence of this core feature. A second approach, a positivist perspective, examines masculinity according to what men are. However, what men are or are presumed to be includes assumptions about gender. A normative perspective creates a standard of what men should aspire to or ought to be. Most men do not meet the standard norm that is the foundation of the normative perspective. Finally, the semiotic approach defines masculinity through a set of symbolic contrasts juxtaposed against femininity. Connell (1995) argued that masculinity should not be defined as an object but rather a lived process and spectrum of relationships whereby men and women engage gender.

Patterns of Masculinity

Rather than a stagnant construct, masculinity becomes an embodied and lived phenomenon. It takes on multiple manifestations that are simultaneously in dialogue and relationship with each other (Connell, 1995). Connell (1995) outlined four intersecting patterns of masculinity prevalent in the United States and Europe: hegemony, subordination, complicity, and marginalization. A hegemonic pattern assumes a dominant position of men and a subordinate position of women. The most socially powerful institutions and individuals define the characteristics of the hegemonic pattern.

Courtenay (2011) asserted that the modern hegemonic masculinity is represented by a European American man who is heterosexual, highly educated, and of high socio-economic status. Hegemonic masculinity assumes other lesser, inferior, or subordinate masculinities. In a subordinate pattern of masculinity certain groups become more legitimate than other groups of men. Men categorized as gay or homosexual are placed in an oppressed position. Heterosexual men of different socio-economic, educational, or racial/ethnic variability than the hegemonic standard may also be deemed as less legitimate and experience greater oppression. A pattern of complicity masculinity involves men who do not completely conform to hegemonic masculinity but nonetheless benefit from it and do not challenge hegemonic assumptions. A fourth pattern of masculinity, marginalization, refers to the relationship between masculinities in dominant and subordinate classes or ethnic groups. To demonstrate this construct, Connell (1995) used the example of the black male athlete who may conform to hegemonic masculinity. The black male athlete's status, however, does not elevate the social position or grant power to other black males who continue to exist the oppressed margins.

Existence on the margins may occasion resistance to hegemonic masculinity with the creation of other forms of masculinities varying in their efforts to conspire with, subvert, resist, or aspire to hegemonic masculinity (Courtenay, 2011). These new masculinities referred to as “oppositional” (Messerschmidt, 1993); “compulsive” (Majors & Bilson, 1992); “compensatory,” (Pyke, 1996); or “protest” masculinities (Connell, 1995) may lead to high-risk behaviors and ultimately poor health outcomes (Courtenay, 2011). The body becomes the medium through which these masculinities are enacted with high-risk behavior including speeding, physical fighting/violence, criminal activity, substance use/abuse, unsafe sexual practices, multiple sexual partners, refusal to access medical services when available, excessive work, compulsive exercise, unhealthy dietary practices, and poor self-care.

A Misrepresented Image

It is uncertain how masculinity influences body image for men with multiple oppressed, identities including racial/ethnic minority, infectious disease, past criminal history, and low educational attainment status. A significant amount of research on the body image captures the experiences of White/Caucasian identified males of diverse sexual orientations or behaviors (e.g., heterosexual, homosexual, gay, MSM, bisexual) but does not exist for racial/ethnic minority identified males of diverse sexual orientations. As a result, the White, Caucasian, or European American male body image experience becomes globally representative of the body image experience of all males. This echoes the homogeneity of NIH funded clinical research studies that excluded women and racial/ethnic minorities until 1993.

Moreover, the prototypical male research subject is a college/university student. In the few cases where male body image research subjects are not recruited from a college/university population, they take part in internet based or paper surveys. The participant usually learns

about the study through a specific network, listserv, and has access to a computer. These participants then become representative of a certain socio-economic or privileged status. The same could be said for the handful of body image studies that include racial/ethnic minority male college participants.

Very few studies have recruited participants from community samples. One such study by Feldman and Meyer (2007) compared eating disorders for White identified heterosexual men ($n = 126$) and participants who identified as lesbian, gay, or bisexual and White ($n = 134$), Black ($n = 131$), or Latino ($n = 131$). Using a community sampling strategy, outreach workers recruited participants throughout New York City. To reduce bias, the researchers eliminated sampling at places that “were likely to over or under represent people receiving support for mental health problems (e.g., HIV/AIDS treatment facilities)” (p. 232). The study found that Black identified gay men (18.8%) had higher rates of eating disorders than Latino identified gay men (15.6%) and White identified gay men (12.3%). When compared to the control group of White heterosexual male participants, gay and bisexual identified men had greater rates of eating disorders. However, this study did not investigate the prevalence of eating disorders in heterosexual men who identified as Black or Latino. Moreover, it did not account for how prevalence rates for eating disorders might be similar or different in Black or Latino identified heterosexual males and Black and Latino identified gay or bisexual males.

Race and Ethnicity Matter

The studies that do exist on body image in racial and ethnic (RE) minority populations obscure the difference between race and ethnicity and largely examine constructs of body image in college populations (e.g., Demarest & Allen, 2000; Schwartz et al., 2010). Psychology researchers may use the terms race and ethnicity interchangeably in what Helms describes as a

“language of convenience” (1996, p. 144). Based on superficial appearance or phenotype, research participants may be artificially classified into a racial or ethnic category. Race and culture have also been subsumed under the umbrella of ethnicity (Helms, 1996).

In the United States, race and ethnicity have distinct characteristics that, if ignored, may render research results meaningless (Helms, 1996; Helms, Jernigan, & Mascher, 2005).

Amongst a large list of what differentiates race from ethnicity, Helms (1996) notes that race lasts throughout generations, does not require the person to do anything to belong, defines a socio-hierarchical position. On the other hand, ethnicity defines a single culture, is mutable, usually disappears after three generations, and requires cultural knowledge to belong (Helms, 1996).

In body image research, these operational distinctions are virtually non-existent. Black, White, and Asian are commonly used as “ethnic categories”. For example, in a study about “ethnicity,” body image, and body size, Cachelin et al. (2002) examined the body experiences of four “ethnic” groupings of men and women ($N = 1229$) classified as Asian, Hispanic, Black, and White. The research category Black could blend research participants from the Dominican Republic, Kenya, and Trinidad even though they do not share similar cultural experiences. Likewise a person identified as Hispanic could also fit into the category of White. The term Hispanic completely ignores sub-group ethnic identification (Loue, 2006). These study participants may have held different dietary habits, beauty ideals, languages, valuing of thinness, obesity, and musculature — all factors affecting construction of body image. A one-size fits all ethnic category denies within/between group differences and sub-group classifications (Burlew, Feaster, Brecht, & Hubbard, 2009).

With minimal research on body image for RE (racial/ethnic) minority men, it is unknown what collateral effect body image may have on health outcomes, quality of life, and

prevention/intervention/treatment for these men (IOM, 2009). This is quite alarming given that men consistently underestimate their risk for illness, injury, and health problems in comparison to women (Courtenay, 2011). In strategic action reports, the United States Department of Health and Human Services (USHHS, 2009) and Center for Disease Control and Prevention (CDC, 2011) highlight that race and ethnicity do matter for health outcomes. These reports summarize the burdens carried by racial/ethnic minority individuals, with 56 million of such identified individuals having limited access to a primary care physician (USHHS, 2009, p.3). RE minority individuals also make up one-third of the population and more than half of those living without health insurance (USHHS, 2009, p. 2). Lack of standardized data collection, categorization, and tracking processes in research has led to the misrepresentation or invisibility of RE minority individuals (USHHS, 2009). This ultimately contributes to lived physical and behavioral health disparities, abridging full human potential (USHHS, 2009).

Operationally defining race and ethnicity becomes paramount to conducting research that has the potential to affect socio-political policy and treatment outcomes (Helms, 1996). If control of body image serves to help men gain control over lived or perceived socio-cultural inequities and powerlessness, it is not known how body image may be experienced for men with multiple disenfranchised identities. For example, what does body image look like for a man classified as Black according to phenotype, identified ethnicity as Dominican, with an experience of immigration, of low socio-economic status, primary language as Spanish, incarceration history, former addictions history, HIV positive and Hepatitis C positive, of a heterosexual sexual orientation, and lives in a community that associates HIV as a gay man's disease? In addition this man would need to take medications for HIV that have the known potentiality to irreversibly change his body shape and size.

Male body image dissatisfaction may increase risk taking behaviors, including sexual risk taking behaviors (McCreary et al., 2007). Most of what is known about sexual risk taking and body image, however, is extrapolated from studies on White gay male samples (see Halkitis, Green, & Wilton, 2007). Examining body image in RE minority men may be of increased salience because: a.) RE minority men suffer from HIV and sexual transmitted infections in numbers significantly disproportionate to non RE minority males (Adimora & Schoenbach, 2005), b.) sexually transmitted infections increase HIV transmission risk exposure (Adimora & Schoenbach, 2005), c.) RE minorities living with HIV/AIDS have the least access to quality medical care (Human Rights Watch, 2011) d.) RE minorities have the highest non-adherence to HIV/AIDS medications thus increasing risk of HIV transmission to their sexual partners (Adimora & Schoenbach, 2002; Proctor, Tesfa, & Tompkins, 1999), and e.) even when individuals do adhere to HIV/AIDS medications, these medications are known, in and of themselves, to have visible, permanent, and disfiguring effects on the body (Gagnon & Holmes, 2008; Hawkins, 2006; Persson, 2004).

For RE minority heterosexual men, sexual risk taking has been linked to assertion of masculinity as a way to cope with multiple lived inequities (Bowleg, 2004; Bowleg et al., 2011). Bowleg et al. (2011) suggests that racial/ethnic minority men should be informed about implicit (e.g., a real man cannot refuse sex with a woman) and explicit culturally transmitted messages about masculinity (e.g., a real man has multiple female partners concurrently). Given culturally specific messages about masculinity and heterosexuality (Bowleg, 2004; Bowleg et al., 2011), the stigma of HIV/AIDS (Varas-Diaz et al., 2005), gay stigma (Brooks, Etzel, Hinojos, Henry, & Perez, 2005), and the erroneous belief that HIV/AIDS is a gay disease in RE minority

communities (Seal & Ehrhardt, 2004), RE heterosexual men suffering from negative body image may increase sexual risk taking behaviors.

If risk taking is associated with body image dissatisfaction, then not addressing body image competencies for REHMHAs may pose an even greater risk than for RE heterosexual males of unknown or HIV negative status (Adimora & Schoenbach, 2005). Aside from the HIV/STI transmission risk for his female partner, REHMHAs may be exposed to another viral strain of HIV/AIDS, if he engages in sex with a female partner infected with HIV. It should be mentioned that women who engage in unprotected heterosexual sex with a man known to be HIV positive are twice as likely to become HIV infected (Dworkin et al., 2009). Biological differences, including vaginal physiology, increases a female's HIV risk. Even for the male perfectly adhering to HAART resistance, exposure to an infected partner through unprotected sex decreases HAART medication effectiveness and increases the possibility of opportunistic life threatening illnesses (Adimora & Schoenbach, 2005). Studying body image for REHMHAs, therefore, becomes paramount to increasing better health outcomes for men and women alike.

Since the beginning of the AIDS epidemic, people living with HIV or AIDS (PLWHAs) acknowledged the vital role of body image for physical, psychological, and sexual health. The body image or attitudes and perceptions of PLWHAs are shaped by the memory of physical manifestations of HIV/AIDS and medication therapies predating the current combination of medication therapies known as HAART (Chapman, 2000; Hawkins, 2006; Persson, 2004). Before HAART, PLWHAs took HIV medications known as antiretroviral monotherapy (Hawkins, 2006). Unlike the more powerful dual medication therapy of HAART, the single medication therapy could not fully suppress HIV replication (Hawkins, 2006). As the virus replicated and the immune system weakened, PLWHAs experienced external physical changes

including muscle and fat wasting, dark raised cancerous skin lesions (i.e., Kaposi sarcoma), fungal infections (i.e., candidiasis), viral warts (i.e., molluscum contagiosum), shingles (i.e., varicella zoster), and enlarged lymph nodes (i.e., lymphadenopathy) (Hawkins, 2006). In effect, these physical changes came to embody the appearance of AIDS --- to PLWHA, to families, to friends, to strangers, to the communities who could read or decipher these outward signs (Chapman, 2000).

Despite the obvious physical transformations experienced by PLWHA before HAART, the body image of PLWHA was rarely explored through scientific research. Turner (1995) was one of the first researchers to examine the intersections of AIDS, body image, and sexuality pre-HAART. Turner noted a public health focus on the sexual actions of gay and bisexual men living with HIV. These men were often portrayed as vectors and intentional transmitters of HIV. In contrast, the sexual actions of persons living with AIDS were thought of as weakened, nonthreatening, and asexual. Turner suggested this absence reflected how the bodies of individuals living with AIDS were valued in dominant socio-cultural currency.

As part of a health needs assessment for AIDS Project Los Angeles (APLA), Turner (1995) conducted 72 quantitative telephone interviews on the health behaviors of PLWHA. In addition to responding to statements regarding general health, participants were asked about their body image and sexual behaviors for the previous 6 months. Participants could respond to these statements according with a Likert scale with “1” indicating strong disagreement and “5” indicating strong agreement. It was hypothesized that sexually active participants would have a positive difference in their social desirability, survival attitudes, and physical self-perception.

Demographic characteristics of Turner’s (1995) sample included 68 men and four women who identified their ethnicity as White ($n = 43$), Hispanic ($n = 16$), African American ($n = 10$),

Asian/other ($n = 3$). Participants also identified themselves according to their HIV transmission risk factor category of homo/bisexual ($n = 55$), heterosexual ($n = 6$), injection drug use ($n = 2$), and unknown transmission risk factor ($n = 9$). With HIV/AIDS data, it was common to identify PLWHA according to risk factor instead of sexual orientation, an epidemiological surveillance data collection strategy originated with the CDC. Of the 72 participants living with AIDS, 69 answered survey questions regarding their sexual activity over the previous 6 months. Of the 69 participants who answered sexual activity questions, 34 reported not having sex and 35 reported having sex. Sexually active participants had a median number of five sexual encounters. Of these, 96% reported “always” using protective measures (i.e., condoms) to prevent HIV transmission.

Turner (1995) found no statistically significant differences in social desirability or survival attitudes when comparing sexually active to non-sexually active individuals. However, significantly lower physical self-perception rates were observed for non-sexually active participants ($M = 19.72$, $t = 64$, $p = 0.02$). The statements most frequently endorsed by these respondents related to feeling unattractive ($M = 17.80$, $t = 3.72$, $p < .001$). Although sexual orientation identification was not specifically accounted for, the majority of participants were male ($n = 68$) and identified their HIV sexual transmission risk factor as “homo/bisexual” sex ($n = 55$). The remainder of men and women in this study are placed into the other transmission risk categories listed including “heterosexual” ($n = 6$), “IDU” ($n = 2$) and “unknown” ($n = 9$). The distribution of the remaining men and women, however, is unknown. Sexual orientation and sexuality are reduced to transmission risk category. Turner, therefore, shows that AIDS did affect sexual activity and body image in a substrate of PLWHA in Los Angeles before effective combination medication treatment options. It is not known how sexual orientation identification

may or may not have interacted with sexual activity rates and physical perception scores for PLWHA. If sexual orientation is part of sexuality, then the multiple facets of identity for PLWHA must extend and be conceptualized beyond HIV transmission risk categories. How did the men and women of the Turner (1995) study define their sexual orientations?

Much still remains unknown about the way PLWHA who identify their sexual orientation as heterosexual experience their body image. Perhaps this could be explained by the historical negation of heterosexual sexual identity in CDC surveillance data collection strategies (Roth & Hogan, 1998). For example, in the CDC HIV reporting system, women testing HIV positive could not identify as bisexual or lesbian (Roth & Hogan, 1998). They could, however, identify a known risk as having sex with a bisexual man (Roth & Hogan, 1998). Heterosexual orientation was forgotten too as heterosexual men testing positive for HIV/AIDS and with multiple reported risk factors were primarily identified in CDC HIV/AIDS surveillance according to what the CDC perceived as their highest risk (e.g., if a man reported heterosexual sex and injection drug use, then injection drug use would trump his report of heterosexual sex) (Exner et al., 1999; Seal & Ehrhardt, 2004). The CDC also did not take into account that individuals identifying as heterosexuals may engage in both vaginal and/or anal sex (Seal & Ehrhardt, 2004). This negation of heterosexual identity has led some to deem heterosexual men living with HIV or AIDS “the forgotten group” of the HIV/AIDS epidemic (Exner et al., 1999, p. 347).

For REHMHA, this “forgotten” identity may add to feelings of internalized stigma and otherness experienced psychologically and manifested physically through negative body image (Chapman, 2002). Often caricatured in Western media outlets as men who knowingly and indiscriminantly spread HIV, REHMHA have been caricatured as criminals with “monstrous masculinity” (Persson & Newmann, 2008, p. 632) and as perpetrators of knowingly and

purposeful spreading HIV/AIDS to female victims (Persson & Newmann, 2008). A pejorative identification has created what Higgins et al. (1999) defined as the “vulnerability paradigm” --- the belief that only heterosexual women and not heterosexual men are disadvantaged by HIV (p. 437). The following media headlines demonstrate how the vilification and criminalization of REHMHA could render this population, unlikeable, invulnerable, and not worth of research, interventions, or support for the unique spectrum of issues that may accompany living with HIV or AIDS: ‘AIDS assassin,’ ‘One man HIV,’ ‘Sexual predator,’ ‘HIV beast,’ HIV timebomb (Persson & Newmann, 2008, p. 634). These highly negative portrayals of REMHA may also have long-term consequences for the way they experience HIV/AIDS and construct their body image. For example, REHMHA may develop complex internal and external (i.e., socioculturally derived) stigmas that include feelings of contagion, criminality, deviant morality, and subjugation (Chapman, 2000). It is known that persons living with HIV or AIDS absorb these dimensions of stigma (Chapman, 2000; Varas-Diaz et al., 2005). It is not known how these stigmas might contribute to the body image of REHMHA as interpreted through the lens of objectification theory (Martins et al., 2007).

Side effects from HIV combination treatment or HAART may further complicate the experience of body image for REHMHA (Chapman, 2002). HAART exists as a paradox for many individuals living with HIV (Persson, 2004). Although HAART suppresses HIV viral load, boosts immune system functioning, and extends life expectancy, it literally could disfigure the body with unpredictable fat accumulation and fat wasting changes (Persson, 2004). Persson (2004) observes that the physical signs of HIV/AIDS pre-HAART were replaced by a new and “unexpected corporality” that became known as lipodystrophy syndrome (p. 47). Because of these physical signs, the body affected by lipodystrophy could reveal HIV status for the observer

or the observing community who could interpret/read its meaning. The gay community gave an alternate slang name to this body, “the look” (Persson, 2004, p. 54). Pejorative slang variations of “the look” exist across languages and cultures including “Amesimamia Msumari” or “standing on a nail” (Tanzania used to describe HIV related fat atrophy/weight loss), “el monstro” or “the monster” (Spanish used to describe HIV itself and the physical and unnatural transfiguration accompanying lipodystrophy), and “the package” (commonly used in U.S. African American communities and English speaking Hispanic/Latino communities) (IRN, 2008).

The research of Collins et al. (2000) is the first study on psychological distress and lipodystrophy syndrome. More than four years after the use of HAART, Collins et al. (2000) observed that the majority of scientific studies on HIV/AIDS recognized the psychosocial effects of HIV but did not research the psychosocial effects of body shape change as a result of HAART. The majority of reports on the psychology of lipodystrophy came from journalistic mediums and captured how lipodystrophy negatively affected body image, quality of life, and self-esteem of PLWHA (Collins et al., 2000).

In a pilot study internet based survey, Collins et al. (2000) gathered the experience of lipodystrophy and HIV/AIDS as told through the narratives of heterosexual women ($n=14$) and gay men ($n = 19$) with self-reports of body transformation attributed to HAART. The results of this survey were intended to develop a purely quantitative study of the psychosocial impact of lipodystrophy syndrome. Participants spoke of internalized stigma, feeling a loss of power and control, social isolation, and reduced sexual interaction. One participant noted loss of locus of control, feeling that his HIV status could be interpreted by his community “ ‘people in my community can tell I am HIV-positive from just looking at my face. It is like the old KS [Kaposi sarcoma] lesions of the nose. It is no secret what this face means’ ” (Collins et al., 2000, p. 547).

This study concluded with a call for more research on body image, quality of life, and evidence based interventions for PLWHA and experiencing lipodystrophy.

After Collins et al. (2000), only a handful of studies extended the research on lipodystrophy, and only two specifically address body image, men, and HIV (Huang et al., 2006a; Sharma et al., 2007). Huang et al. (2006a) examined body image for HIV positive males using quantitative methodology. The study hypothesized that the sample of 110 men with HIV and lipodystrophy would have heightened levels of body image dissatisfaction and reduced quality of life. Seventy-eight men identified their sexual orientation as men having sex with men (MSM), and it is not clear if any of the other 22 men identified their sexual orientation as heterosexual because men not identifying as MSM were coded as “other” (Huang et al., 2006a, p. 670). Participants answered a body image quality of life questionnaire (i.e., Body Image Quality of Life Index, BIQLI), a body image dissatisfaction questionnaire (Situational Inventory of Body-Image Dysphoria, SIBID-S), a health state scale (i.e., The Euroqol Visual Analogue Scale, EQ-VAS), indicated locations of any bodily changes, and stated if they thought their body changes might reveal their disease status to others (coded as “yes” or “no”) (Huang et al., 2006a). Study physicians also evaluated the presence or absence of lipodystrophy through physical examination.

The results of Huang et al. (2006a) indicated that lipodystrophy was associated with poor body image. However, both body image questionnaires used in this study — the BIQLI and the SIBID-S — were normed/validated with samples of White college students who were primarily female. The body image experiences of White college students most likely do not match the dimensions of body image experience for PLWHA in general and REHMHA specifically (Burgoyne et al., 2005). Additionally, Huang et al. (2006a) did measure participants CD4 count

(i.e., measure of immune system functioning) and HIV viral load (i.e., measure of the HIV virus in the body) but did not specifically ask participants if they were taking HAART before or at the time of study participation.

Sharma et al. (2007) is the only study known to examine body image in a mixed sample of older men living with HIV or AIDS ($n = 322$) and older men identified as being at risk for HIV infection ($n = 228$). All subjects were 49 years of age or older. Through a cross sectional analysis of an ongoing longitudinal study, the prevalence and factors associated with negative body image were examined. The study used four possible sexual orientation identity categories — “heterosexual,” “bisexual,” “homosexual,” and “none of these” (Sharma et al., 2007, p. 243). Measures included a demographic interview, evaluation of depressive symptoms using the Center for Epidemiological Studies Depression Scale (CES-D), and audio computer assisted self-interviewing (A-CASI) for participant information thought to be sensitive by the researchers (e.g., illicit drug use, sexual history, and body image). Body image was specifically assessed by the participants either agreeing or disagreeing with items said to capture aspects of body image.

Sharma et al.’s (2007) results indicated that 50.4% of participants with lean/normal body weights perceived themselves to be too thin whereas only 26% of overweight participants perceived themselves to be too heavy. HIV-infected men reported themselves to be less sexually active than non-HIV men in the previous six months. Negative body image was associated with adherence to HAART, lipodystrophy, higher BMI, depressive symptoms, erectile dysfunction, and low self-rated health.

Although HIV positive participants reported adopting celibacy or lessening sexual activity, no differences existed in sexual dysfunction or attribution of body shape changes between HIV positive and non-positive groups. A possible explanation could include lack of

health literacy about lipodystrophy or potential effects of HAART on fat distribution changes. They may have blamed themselves for body changes, potentially leading to negative body image. Failure to inform patients about potential negative body changes and HAART was documented in a qualitative study about the process of physical transformation and HAART in Canadian sample of HIV positive women ($N = 14$) (Gagnon & Holmes, 2011). Failure to attribute body shape changes to HAART may be reflective of the small number of participants actually taking HAART in this study. Only 55 of the 322 HIV positive participants (17.08%) reported using HAART in the previous 6 months. Therefore, participants may not have experienced body shape changes because of HAART non-adherence or lack of access to HAART, a reality for many racial/ethnic minorities living with HIV/AIDS (Human Rights Watch, 2011).

Regardless of HIV status, participants identifying as other than heterosexual were more likely to report that they were too heavy (Sharma et al., 2007). In communities with high rates of HIV, this may be desirable as thinness could have an association with stigmatized representations of AIDS wasting. Perceptions of muscle gain or loss, an area of focus in body image literature on heterosexual White/Caucasian samples, were not accounted for in this study (McCreary et al., 2007). It is also uncertain what specific dimensions of body image were tested by this study's survey statements on body image. Sample body image statements seem to focus solely on shape and size (e.g., "overall I feel satisfied with my body shape," "overall I think I am too heavy"). For PLWHA, body image is made up of more than shape and size and includes the experiences of illness, identity, stigma, and socio-cultural politics — 30 decades of metaphorical, lived, and embodied meanings (Crawford, 1994; Chapman, 2000; Persson, 2004). Lastly, the body image results of this study may not be applicable to REHMHA over 49 years of age.

Biological sex and disease status may influence patterns of fat gain or loss for PLWHA (Andany et al., 2011), which is important in understanding why males living with HIV or AIDS (MLWHA) and taking HAART or having a history of taking HAART may experience different body shape changes than females living with HIV or AIDS and taking HAART (FLWHA). Kotler, Rosenbaum, Wang, and Pierson (1999) found that HIV positive men had less body cell mass, fat free mass, and fat than HIV negative male and female control groups. Further, HIV positive males taking HAART demonstrated a statistically significant lower mean weight, body mass index (BMI), and decreased triceps measurement when compared to HIV negative male controls (Kotler et al., 1999).

In a Canadian sample of PLWHA taking HAART ($N = 778$), Andany et al. (2011) found that HIV positive males taking HAART ($n = 659$) reported more outer region fat loss or peripheral lipotrophy ($p = .01$) while HIV positive females taking HAART ($n = 119$) reported more central region fat gain or central lipohyperatrophy ($p < .0001$) and mixed fat redistribution ($p < .0001$). Several physiological and biological factors may account for the differences in the way HAART is metabolized and eliminated in HIV positive males and females. These factors may include biological differences in hormonal levels, body weight, and body fat composition between males and females (Andany et al., 2011).

These findings may highlight important information about weight gain/weight loss in the HIV positive male population as opposed to HIV positive female population and the general HIV negative male and female population. A 2009 national Center for Disease Control (CDC) study of 23 U.S. health jurisdictions found that the age adjusted obesity prevalence rates for MLWHA (17.7%) are lower than a male HIV negative comparison group (36%), and for FLWHA, the age

adjusted prevalence of obesity rate was higher (40%) than a female HIV negative comparison group (36%).

Fat changes accompanying adherence to HAART may also be influenced by factors associated with racial or ethnic identification (the terms race and ethnicity are used interchangeably). Andany et al. (2011) also explored ethnic differences of PLWHA Canadian participants reporting lipodystrophy. Participants self-reported their ethnicity according to the categories White, Black, Latin American, South Asian, Southeast Asian, Arab/West Indian, Aboriginal, other, do not know, or refused to answer; self-reported ethnicity was then collapsed into three subcategories, Black, White, and other. Results from Andany et al. (2011) indicated that White participants were more likely ($p = .004$) to experience peripheral loss of fat (45%) as opposed to Black participants (30%) or the Other participant group (36%), White participants were also more likely to have higher rates of fat wasting in the legs (43% vs. 27% vs. 32%; $p = .003$), buttocks (41% vs. 28% vs. 29%; $p = .008$), and abdomen (49% vs. 46% vs. 45%; $p = .003$).

The reduction of the purported ethnic variables into a three racial category variables obscures within and between group differences of lipodystrophy, attributing fat changes experienced as a result of lipodystrophy to race instead of socio-cultural/environmental/medical factors. For example, if a person identified as “Other” is unable to afford healthier food options than White participants, then he/she might have more fat gain from medication than fat loss. Moreover, it may show underlying researcher assumptions about body image, race, and HIV. Helms et al. (2005) notes the variable of race shows “the researcher’s underlying beliefs about the nature of race even though racial categories cannot accurately reflect such beliefs” (Helms et al., 2005, p. 30). This is of significance to studying body image and lipodystrophy in PLWHA as

the generated racial classification categories may obscure cultural patterns/norms (e.g., food types, eating patterns, immigration status, collectivistic orientations, socio-economic status) impacting eating patterns, medication adherence, and consequently the way the body living with HIV or AIDS both looks and is experienced, individually and by his/her community.

The first generations of HIV medications were generally studied on homogenous samples of White males. Despite the 1993 mandated inclusion women and minorities in NIH funded clinical research, the exclusion of racial/ethnic minority individuals and women persists to the present day (IOM, 2012). As noted, the idea of White males as synonymous with all human beings including racial and ethnic minority males may have long term and detrimental consequences for REHMA. In the earliest HIV medication clinical trials, persons identified as Black made up 34% of all AIDS cases but only 7% of NIH HIV/AIDS study participants. Persons identified as Hispanic made up 17% of all AIDS cases but only 9% of NIH research subjects (Mays et al., 2001).

In a recent surveillance interview study conducted by Sullivan, McNaghten, Begley, Hutchinson, and Cargill (2007) in 15 U.S. states, it was noted that only 17% of HIV positive racial/ethnic minority individuals ($N= 6,892$) had ever participated in a research study, with the odds of participating in clinical research studies lowest for Black and Hispanic males. RE HIV positive males surveyed cited that their primary reason for not participating in a study was that they were unaware of available studies or not offered enrollment (Sullivan et al., 2007). Sullivan et al. (2007) did not account for sexual orientation of RE HIV positive males but rather by their transmission risk for HIV infection. Not studying the specific biological, physical, and psychological effects of HIV medications, including the body image experiences of REHMA, highlights the extent of disparities. These disparities not only affect prevention, intervention, and

treatment opportunities but may literally impact HIV medication adherence, potentially decreasing life expectancy and the quality of life lived.

Chapter III

Method

Researchers

The primary researcher is a female doctoral student in counseling psychology with a background in counseling racial/ethnic minority individuals living with infectious disease in both Spanish and English. She has worked with people living with HIV or as AIDS defined (PLWHA) for over five years. She has training in multicultural considerations in psychology, HIV/AIDS, and qualitative methods. Six additional interdisciplinary research team members worked on the current study. Collectively, research team members had up to 20 years working with PLWHA in their respective disciplines including public health, social work/case management, HIV prevention and outreach, and paraprofessional volunteers. In addition, the research team represented a spectrum of diversities related to disease, immigrant, linguistic, sexual orientation, socio-economic, and racial/ethnic minority identification. The research team participated in all phases of research including weekly research team meetings, transcription checking, memo writing/journaling, coding, data analysis, and will participate in distribution of results. All team members received research training in human subjects from the Collaborative Institutional Training Initiative (CITI) and have participated as research team members in quality improvement initiatives and the primary investigator's prior qualitative research study (Vella, 2015).

Interpretative Phenomenological Analysis

Interpretative Phenomenological Analysis (IPA) is a qualitative methodology that examines the lived experience or understandings of participants in respect to a particular phenomenon or phenomena (Smith et al., 2013). IPA has been shaped by three theoretical

influences — phenomenology, hermeneutics, and idiography (Smith et al., 2013).

Phenomenological philosophy contributes to IPA emphasis on lived experience of the participant or attempting to enter into the participant's "life world" to understand "what it is like" (Larkin, Watts, & Clifton, 2006, p. 104; Smith et al., 2013). Hermeneutics has been described as a "theory of interpretation," contributing to the interpretative component of IPA (Smith et al., 2013, p.21). Within IPA analysis, a double hermeneutic manifests as "the participants are trying to make sense of their world; the researcher is trying to make sense of the participants trying to make sense of their world (Smith & Osborn, 2008, p.53). Idiography, the third influence of IPA, highlights the importance of the particular (Smith et al., 2013). In IPA, participants are purposefully chosen because of a particular phenomenon or process that they are undergoing. While idiography honors the unique experience of each participant, it acknowledges that individuals are "persons in context," deriving meaning from relationships and the world that they inhabit (Larkin et al., 2006, p.108).

IPA has been used extensively in clinical, health, and social psychology with research topics that include health and illness, sex and sexuality, psychological distress, and life transitions and identity (Brocki & Wearden, 2006; Smith et al., 2013). It has allowed researchers and participants to go beyond a biomedical understanding of health related phenomenon or the privileging of quantitative medical discourses to explain markers of health and illness. IPA may be an especially important analytic approach for individuals living with HIV or as AIDS defined. As Wong and Ussher (2008) noted, the majority of HIV/AIDS research has analyzed health related experiences of PLWHA according to biomedical indicators. For example, the quality of life of PLWHA may be measured by how effectively a HIV medication seems to be working as

indicated by HIV viral load or white blood cell counts. A sole examination of clinical markers, however, ignores the lived experience of health and illness.

Participants

Congruent with the IPA methodology, participants were purposefully chosen for this study based upon specific inclusion criteria (Smith et al., 2013). The sample was planned to include up to 30 men living with HIV or AIDS, identifying as having a heterosexual sexual orientation and as racial/ethnic minorities, and currently taking or having taken HAART for a minimum of six months. It should be noted that the sample was planned to include up to 30 men in order to meet the requirements of the hospital IRB, to request the appropriate grant funding for this study, and with a projected consideration of how many participants might be needed to accurately represent and balance the demographic characteristics of this particular clinical population.

A sample of 21 participants was recruited from a hospital-based infectious disease clinic (see Table 1 for demographic characteristics; Appendix 1 for the recruitment flyer) from an identified potential sample of 50 men. Recruitment of participants was not anticipated to be difficult for several reasons. As noted, research team members had a range of experience (i.e., 3 years to 20 years) working directly with the client population at the hospital site and had developed a significant rapport with the client community. The hospital site provides services to over 1,000 clients living with HIV or as AIDS. Over 60% of these clients identify as racial/ethnic minorities and of heterosexual sexual orientation. Potential participants were identified through case managers, physicians, and other clinic support staff. In the current study, participants were recruited within two months with enrollment met with 21 participants and the consequent termination of recruitment. Of the 50 potential participants identified by clinic staff,

35 met the inclusion criteria, and 21 were enrolled and participated per team consensus, issues identified in the most previous wave of interviews, and with respect to balancing demographic characteristics of the sample population. Fifteen potential participants did not respond to the research invitation. The age demographic of the 15 potential participants who did not respond to the research invitation was early 20s and early 30s.

IPA studies range in sample size from one participant for a single case study (see Bramely & Eatough, 2005) to 42 participants (see Reid, Flowers, & Larkin, 2005). Smith et al. (2013) noted that there is no one correct sample size for IPA. Smith and Osborn (2008) outlined several factors that may contribute to choosing a sample size including the researcher's commitment to case study analysis and reporting, the richness of each case, and time constraints of the researcher. For this study, up to 30 participants were planned for recruitment, and recruitment, as decided by the team, ended at 21 participants.

When using IPA with larger sample sizes, the researcher shows how primary themes manifest and reoccur at the group level (Smith et al., 2013). Detailed individual participants' experiences are then utilized to present evidence for the nuances and sublets of the reoccurring group themes (Smith et al., 2013). Brocki and Wearden (2006) acknowledged that the cyclical and iterative nature of IPA suggests that the research process could technically continue in perpetuity as participants' responses are examined with respect to new voices and perspectives of the potential next interview. They also noted the importance of "the researcher acknowledging limits to the representational nature of their data" (p. 95). For this study, recruitment and enrollment ceased when 1.) a nuanced (i.e., based on the individual participant) though overt repetition of issues was initially noted in the transcription of interviews with discussion in team

meetings; 2.) new potential participants meeting the enrollment criteria would have been over-representative of the demographic characteristics of those who already participated.

Participants were chosen based on their diversity of experience that included diversities in age (e.g., a balance of older and younger participants), race/ethnicity (e.g., Black, White, American Indian, Hispanic, Latino, Pacific Islander, Puerto Rican, Dominican, Kenyan), disease status (e.g., living with HIV or AIDS), years living with HIV or AIDS, months or years taking HAART, relationship status (e.g., married, partnered, separated, divorced, widower), occupation (e.g., student, professional, unemployed, disabled). Although socio-economic status was considered, it was anticipated that the majority of participants would be living at or below the poverty line as 99% of clients served at the hospital site meet these socio-economic demographics. Participants were required to be patients/clients at the hospital site.

Instruments

Semi-structured interview. An in-depth semi-structured interview served as the primary instrument. Semi-structured individual interviews are the main data source for IPA (Reid et al., 2005) studies. In IPA, the semi-structured interview has been thought of as “a conversation with a purpose” (Smith et al., 2013, p. 58). Smith et al. (2013) suggested that the semi-structured interview follow a framework to better ensure that the phenomena or process under investigation is adequately covered. Thus, questions generated from this semi-structured interview format were broadly based on the body image framework of Thompson (1990) and adapted to meet the potential concerns of REHMHA. Thompson’s body image theory (1990) asserts that a person’s body image is made up of three domains. The perceptual domain may be constructed from the internal or self-understanding and external or the social understanding of the body’s shape and size. Interview questions and probes for the perceptual domain asked the

participant about his physical shape and size before his HIV diagnosis and then after his HIV diagnosis and taking HAART. The behavioral domain may encompass how a person's feelings about his body, including bodily changes, influence behaviors. Interview questions and probes for the behavioral domain asked the participant about his feelings about his body before his HIV diagnosis and then after his HIV diagnosis and taking HAART. After the participant's feelings were better understood, the interviewer asked questions and probes concerning potential behaviors affected/influenced by his feelings. The third body image domain, the subjective domain, may elicit information on how the participant views the social investments placed on the HIV positive body. Interview questions and probes for the subjective domain asked the participant's views on social investments placed on the HIV body including his perceptions of how the HIV body is viewed in journalistic mediums, television/movies, with a REHMHA celebrity figure, Magic Johnson, and for sub-groups of HIV positive male populations (e.g., the social valuing between gay identified and straight identified HIV positive or AIDS defined males of varying race and or ethnic identifications). Finally, the interviewer asked the participant if he would like to clarify any part of his interview responses or if he needed the interviewer to clarify any aspect of the interview; if he wanted to add anything to his interview; if he felt that there should be anything taken out of the interview; and if he felt anything additional might be helpful to include for other men who would participate in the study.

As Smith et al. (2013) noted, IPA research questions may engage with theory but they do not test theory. In this study, Thompson's theory on body image was used as a conceptual framework or starting point through which REHMHA could begin to speak about the meanings of their body individually and interpersonally. It was not used with the purpose of proving, disproving, or testing Thompson's theory of body image. The semi-structured interview was

anticipated to assist the researcher in providing a detailed account of the lived experience of body image for REHMHA (Smith et al., 2013). It was thought that without an anchored but flexible framework of body image, body image could not be appropriately explored. For example, asking a question such as “can you tell me what body image means to you?” might prove ambiguous for the participant and ultimately not assist in reaching the lived experience of the participant. Considering the review of literature on body image as complex and multilayered phenomenon for PLWHA (e.g., Chapman, 1998), it was thought that the domains of body image as proposed by Thompson (i.e., the perceptual, the behavioral, and the subjective) could provide a broad, flexible, and guiding framework to enter the participant’s life world and gather data to sufficiently answer the research question.

Using Thompson’s definition of body image, the researcher interviewed participants in an individual semi-structured format. The interview included open-ended questions and probes on (a) the perceptual, (b) the behavioral, and (c) the subjective facets of body image (see Appendix 2 for semi-structured interview questions). The interview protocol was developed by team members and was piloted on two REHMHA and one man living with HIV who identified as heterosexual and European American to compare and contrast reactions to questions/probes generated for the three domains. The piloting of the interview protocol was voluntary with no financial or compensatory incentive given for feedback.

Before interviews began, it was emphasized to the participant that there were no right or wrong answers (Smith et al., 2013). Questions were approached in an open and expansive matter, without rigidity, and allowing the interaction to access a deeper level of the participant’s experience. It was very important for the interviewer to follow the rhythm of the participant. As each participant brought unique insights and considerations, the interview was refined or

elaborated upon as concepts or categories came into awareness, as participant “objects of concern” (Larkin, Watts, & Clifton, 2006, p. 111). Not every question, prompt, or interview sequence was relevant to each participant (Smith et al., 2013). In order to truly delve into the participants’ lived experience, the researcher sought to be open to the unpredictability of what the participant could bring to research topic through the interview (Smith et al., 2013). Some participants automatically approached the interview in a very detailed and specific way. For example, several participants noted their lack of presence in research, showed a strong desire to speak on the research topic, and started with more specific content (e.g., detailing how the shape and size of their body changed post HAART) without interview prompts. As these participants started with specific examples relevant to them, other generalized understandings were explored later in the interview (e.g., using prompts to assist in accessing the participants sense of what the perfect shape and size for a man’s body should be).

Demographic questionnaire. The demographic questionnaire asked participants to report disease status (i.e., HIV positive or AIDS defined), years living with HIV or AIDS, length of time taking HAART, relationship status, self-identification of skin color, racial/ethnic/or national identity status, primary and secondary languages, educational level, employment status, and income level (see Appendix 3). Three voluntary pilot participants (see semi-structured interview section) provided feedback on the demographic questionnaire. Additional feedback on the demographic survey was elicited from participants. Participants did not have additional insights or considerations to add to the demographic survey.

Body image questionnaire. The body image questionnaire asked participants to report exercise activity, perceptions on diet, surgical cosmetic procedures before known HIV infection, surgical cosmetic procedures after known HIV infection or AIDS defined status, consideration of

surgical cosmetic procedures if covered by medical insurance, dietary supplement use to increase musculature, injection steroid use, shaving habits, and tattoos/tattoo placement (see Appendix 4). Three voluntary pilot participants (see semi-structured interview section) provided feedback on the body image questionnaire. Participants were asked to provide additional feedback on the body image questionnaire and stated that they did not have further suggestions, comments, or concerns.

Perception of lipodystrophy scale (PLS). The Perception of Lipodystrophy Scale (PLS) is an analogue scale, created for this study, to measure self-perception of fat loss or fat gain from HAART. As shown in Appendix 5, the participant was instructed to place an “x” within the gradient circles on an analogue scale that best represents their perception of fat gain or fat loss on body regions/parts including the face, the chin, the neck, the back, the chest, the abdomen/stomach, the upper leg, the lower leg or calves, and the buttock. Possible item responses included seven choices, ranging from extreme fat loss (as represented by a colorless circle) to extreme fat gain as represented by a black filled in circle. The PLS responses were coded from 0-3, with 3 points given for a response of extreme fat loss or fat gain, 2 points for moderate fat loss or gain, 1 point for mild fat loss or gain and 0 points for no report of fat loss or gain. Participants had the option to report both fat loss and fat gain in the same bodily region. For example, a participant may have noticed areas of his chest or pectoral region that show accumulations of fat as well as fat wasting. Points were added for each analogue scale response with a total score obtained. Participants scored a minimum of 0 (e.g., if no fat loss or fat gain is reported) to a maximum of 6 (e.g., if both extreme fat loss and extreme fat gain is reported). Higher scores represent a greater perception of lipodystrophy. Three voluntary pilot participants (see semi-structured interview section) provided feedback on the PLS. The PLS administrator

asked participants for feedback on the PLS, and participants did not have further suggestions, comments, or concerns.

Procedure

After this study received IRB approval from both Lehigh University and the hospital site, potential participants were notified about the study by hospital staff members. They were given a research flyer outlining basic inclusion criteria and a summary of the study (see Appendix 1 for recruitment flyer). Individuals either called or met with Michele Vella to speak about the inclusion criteria. If a potential participant met inclusion criteria, his name and basic demographic information were recorded and brought back to the research team during a weekly research team meeting. Because the team employed a purposeful sampling strategy (Patton, 1990; Smith et al., 2013), it aimed to include as many diverse voices as possible (e.g., ethnic identity, years living with HIV, age), and invitations to eligible individuals to enroll in the study were based upon the research team's consensus. Thus, not all participants who met the inclusion criteria were invited to enroll.

Recruitment of participants lasted for two months. Staff members identified 50 potential participants and gave them recruitment flyers. The first five potential participants identified by staff members, all of whom represented diversity in demographics and met the inclusion criteria, enrolled and subsequently participated in the study. Within a one-week timeframe, team members transcribed the various waves of participant interviews. The initially identified issues were brought back to the next team meeting with a review of new potential participants who met the study criteria and wanted to enroll. In these team discussions, new participation was determined by the contemplation of the initial identified issues of the most recent wave of completed interviews and the team's sense of the unique demographic characteristics and voice

that the potential participant could bring to the study. A second determining factor of selected participation was timing or when the potential participant inquired about the study and was determined to meet inclusion criteria. For example, if two potential participants of similar demographic characteristics decided to enroll, the potential participant who inquired about the study first was chosen to participate. On each potential participant inquiry, both the date and time were written. This pattern repeated until the team determined that no new initial identified issues were emerging and that the remaining participants interested in enrolling were already sufficiently represented in the sample population. From their initial inquiry, potential participants were informed that not everyone who met the inclusion criteria would be invited to enroll. The primary researcher either called or met with these potential participants to thank them and let them know that they would not be asked to enroll in the study.

After enrolling but before the start of the questionnaire administration and interview, participants were administered an informed consent document (Appendix 6). A copy of the signed informed consent document was given to the participants. After informed consent was obtained, participants completed the demographic questionnaire (Appendix 3), the body image questionnaire (Appendix 4), and the PLS (Appendix 5). After completing these measures, the interview portion of the study was conducted (see Appendix 2). The interview portion of this study ranged in time from 1-1.5 hours. In total, the study did not take more than two hours for both the questionnaire administration and semi-structured interview portion. Participant individual interviews were conducted by Michele M. Vella in an office at the hospital site.

The interviewer wrote field notes during the interview in an effort to increase a reflexive engagement with the data (Smith et al., 2013). These notes included verbal and nonverbal cues, reflections, and impressions of the interview. The interview was audiotaped and later transcribed

for analysis. Within the transcription, participants were identified by the letter “P” for participant and an assigned study number. All identifying information was de-identified to maintain maximum confidentiality. De-identified information included first name, last name, age, names of family members or friends, location/place of birth, past addresses, occupations, employers, and places where the participant receives or had received care. To account for the de-identified information in the transcription, brackets were placed to make a notation of the general information the participant was speaking about. For example, if the participant stated: “I was working at ____ [specific name of employer],” the transcription would read “I was working at [generalized phrase noting place of employment with no specific identifier] at that time.” It should be noted that all team members were trained in and complied with the Health Insurance Portability and Accountability Act (HIPAA) as employees of the hospital. Interview transcriptions were checked by one team member for accuracy of transcription. Team members alternated in reviewing transcribed interviews so that each team member reviewed a subset of the transcriptions for accuracy. The team members listened to the original audio recording and examined the corresponding transcription. Any transcription errors were noted and corrected. The transcription of the semi-structured interview and the transcription accuracy check took no longer than one week from the initial interview. The audio recording was then permanently deleted. In the transcription, participants were identified by the letter “P” for participant and a study number. All identifying information was de-identified to maintain maximum confidentiality.

All transcriptions, demographic questionnaires, and the PLS were entered into NVivo 10 qualitative software to assist in the management of the data and coding process. All team members had access to NVivo 10 software on their password protected computers issued by the

hospital site. The hardcopy version of these study documents were kept in a double locked filing cabinet as they needed to be retained for potential IRB auditing from the hospital site and Lehigh University. The primary researcher will disseminate or share results with participants through individual meetings based on the participant's interest and arranged according his preferred time and availability.

Overview of Analysis

A descriptive overview of demographic characteristics and perceptions of fat weight and/or fat loss from antiretroviral HIV medication adherence was generated from analyzing data of the demographic questionnaire, body image questionnaire, and PLS using SPSS 21. All other forms of data (i.e., each semi-structured interview transcript, participant feedback, field notes, self-reflective memos, and notes from team meetings) were analyzed using an IPA approach as outlined by Smith et al. (2013). First, a Microsoft Word document template was created with three columns. The middle column included the original transcript with participant statements indicated by the letter "P" and researcher statements indicated by the letter "I" as well as other data forms (i.e., participant feedback, field notes, self-reflexive memos, and notes from team meetings) that corresponded to the participant being analyzed. The third column was entitled "exploratory comments", and the first column was entitled "emergent themes." This template was first placed into NVivo 10 software, a software tool that assists in the management of data for qualitative methods such as IPA. These forms of data were uploaded into NVivo 10 software from a Microsoft Word document on the research team member's password protected computer or typed directly into and saved in a research project folder of the NVivo 10 software. After the transcribed interviews and other participant data sources (middle or second column) were placed into the Microsoft Word document template, they were uploaded into NVivo10. The data were

then passed through an adapted series of six analytic phases as modeled by Smith et al. (2013). During these analytic phases, the third column for exploratory comments and the first column for emergent themes of the Microsoft Word document were utilized. NVivo software was used to help track the analytic process of each research team member. As noted by both Smith et al. (2013) and Brocki and Wearden (2006), there is not one singular or prescriptive methodology for IPA analysis with considerable flexibility and creativity for how the researcher(s) might approach the analysis. Given these considerations and the large sample size of the present study, our research team was guided by the suggestions of Smith et al. (2013) for working with larger sample sizes. These differences will be noted in the outlined steps where applicable.

Six steps of analysis. The IPA coding analytic process followed the six steps outlined by Smith et al. (2013) that include: reading and re-reading; initial noting; developing emergent themes; moving to the next case; and looking for patterns across cases (each step is described in detail below). As noted, Smith et al. (2013) point out that these six steps are not meant to be prescriptive or linear but rather flexible and creative. They provide a possible approach rather than a specific formula. At each step or phase of participant selection and analysis, team members met weekly to discuss potential participants' inclusion or the analytic process.

After participants were interviewed and completed the surveys/questionnaire, team members checked in with participants to ensure accuracy of information. Team members had ample opportunity to check in with clients given the high level of client contact in the hospital affiliated food bank, doctors', case management, adherence, and behavioral health appointments. If a team member needed to speak with a participant for additional information, he or she stated that they would like to speak with the participant, and then the participant was brought to a confidential office space. It was noted that several reoccurring types of check in encounters

occurred in this study including: speaking with participants about the meaning of word choice or how a word was used, soliciting more information about the context of a particular experience(s), or attempting to better understand cultural views or perceptions influencing the participants' responses. During check in encounters, the team member wrote notes and showed them to the participant for accuracy. The notes were then placed into comments column and/or thematic column for incorporation into discussion, data coding, and analysis.

Reading and re-reading. The first analytic phase of IPA was reading and re-reading. Reading and re-reading required research team members to actively engage with the participant data. During this phase, the six research team members were assigned the four to five participants each with at least two team members sharing the same participant. Additionally, the primary researcher was assigned all 21 participants. All researcher team members were provided with copies of transcripts for the participants that they were not assigned to. During the reading and re-reading phase, research team members were responsible for their assigned cases and were also responsible for reading the transcripts of the cases that they were not assigned to for full participation of the research team in the analysis steps. For their assigned participants, the research team members listened to the audio recording of the participant interview as the transcript was read (Smith et al., 2013). During reading and re-reading the research member drew upon field notes, past self-reflexive memos, and new self-reflexive memos. The research member noticed the interview structure, the chronological structure of the participant's responses, rapport building between interviewer and interviewee, the rhythm of the participant's responses, and how the participant generated meaning as he moved from generic explanations to specific details (Smith et al., 2013). Self-reflexive memos were especially important in this step as well as throughout all phases of analysis, assisting the researchers in thinking about their pre-

conceptions, biases, and the way that they might consciously or unconsciously bring them into the analysis. In order to reduce bias the reflexive awareness of the role of the researcher was necessary, having other members participate and scrutinize the analytic process, and checking in with participants were necessary (Brocki & Wearden, 2006).

At the end of the reading and re-reading phase, team members met in the weekly meeting to discuss this step of analysis. In addition, notes for this phase were placed into a Microsoft Word document that was subsequently imported to NVivo software. NVivo software assisted research team members of keeping track of each research team member's individual process and served as a hub for accessing information outside and inside of weekly meetings. In summary, reading and re-reading provided the researchers the opportunity to enter into the participant's life and process of meaning making (Smith et al., 2013).

Initial noting. After reading and re-reading, the researchers entered the second step of the IPA analytic process, initial noting. Initial noting required the examination of both content and language (Smith et al., 2013). The researchers wrote comments in the third column of the document template entitled "exploratory comments." These comments were both descriptive (the phenomenological aspect of IPA) and interpretative (the hermeneutic aspect of IPA). Descriptive noting highlighted the concerns or what mattered to the lived experience of the participant (e.g., relationships, processes, values, principles; Smith et al., 2013, p. 83). Interpretative noting required the reflexive engagement of the researcher. These notes attempted to highlight how and why participants had particular concerns about the phenomena under investigation and the possible meanings generated from such concerns (Smith et al., 2013). Here again, the participants utilized both self-reflexive memos and bracketing to increase the credibility of the analysis. Other types of comments that included during initial noting were

linguistic comments that noted the participants' use of specific language such as metaphors, word choice, word repetition, or language fluency (Smith et al., 2013). Each research team member completed the initial noting for the participants that they were assigned to. The initial noting was discussed in team meetings. As in the reading and re-reading phase, each research team members initial noting was placed in a Microsoft Word document that was subsequently imported into NVivo 10 software. This allowed for research team member accessibility of the process within and outside of weekly team meetings.

Developing emergent themes. The researchers used both the interview data and the data generated from the initial noting to focus on the next research phase, the developing of emergent themes. At this phase, the researchers focused on specific chunks or blocks of the transcript and initial notes, analyzing exploratory comments and identifying emergent themes (Smith et al., 2013). As notes were turned into emergent themes, a concise statement was created that reflected the chunk or block of the transcript and initial notes. Emergent themes reflected the participant's words and thoughts as well as the researchers' interpretation of these words and thoughts. As Smith et al. (2013) noted, emergent theme titles are usually not something that the participant explicitly states or suggests but could be poignantly reflected in the actions or words of what the participant says or does (Smith et al., 2013). In this study, emergent themes were noted in the first column of the Microsoft Word document template and ordered chronologically or according to the order they appeared within the participant's semi-structured interview.

Each research team members' emergent themes were placed in their Microsoft Word document and imported into NVivo 10 software as in previous analytic steps. At this phase, research team members presented their emergent themes in weekly team meetings, with weekly team meetings lasting 2-2.5 hours and discussion in-between meetings and two participants' data

discussed per weekly team meeting. Research team members had the charge of presenting their assigned research participants. Research team members with different assigned participants still read these transcripts. At this phase, team members presented the emergent themes of their assigned participants and brought along their self-reflexive journals and memos. A section-by-section reading was performed with the team whereby the team members assigned the participant discussed their emergent theme titles and rationale for emergent theme titles. If there was a disagreement on the emergent theme title, team members discussed the disagreement and examined the section in disagreement more closely. Where applicable, the team member assigned the participant would go back to the participant to check in with the participant about any questions or concerns of the team. The participant check-ins helped significantly, allowing for consensus to be reached for all team members on emergent theme titles. Final emergent themes for each participant were gathered into a Microsoft Word document and were imported into NVivo 10 software these included final emergent themes listed for each participant as agreed upon by the team.

Searching for connections across emergent themes. After the researchers noted emergent themes, they searched for connections across emergent themes. The research team was guided by the recommendations of Smith et al. (2013) for working with larger samples. This task was accomplished through creating models and maps of patterns and relationships of emergent themes (Smith et al., 2013). Researchers formed clusters of related themes whereby “some themes will act as magnets, pulling other themes towards them” (Smith et al., 2013, p. 96). These themes then “act as magnets” attracting the other themes form the super-ordinate, primary, or core themes of the participants’ accounts. Once the connections of emergent themes were identified through super-ordinate themes, the researchers made a graphic representation of the

super-ordinate theme with the cluster of emergent themes underneath. This graphic representation was accomplished with tables, charts, and sketched out models that included words or excerpts from the participants that elucidated the super-ordinate and cluster of emergent themes (Smith et al., 2013).

Moving to the next case. As the team was working with a larger sample, two to three participants transcripts were examined each week with the examination eventually creating a Microsoft Word document imported into NVivo 10 software with emergent and super-ordinate themes. Thus, this step of an analysis was adapted to account for the larger sample and guided by the recommendations of Smith et al. (2013).

Looking for patterns across cases. In the last step of IPA analysis, the research team listed super-ordinate themes and emergent themes at the group-level while noting how each participant manifested each differently according to their nuanced or varied responses. For this step, measuring re-occurrence across cases was important. The status of a super-ordinate theme and emergent themes was determined to be recurrent if they were present in at least one-third but preferable one-half or more of all cases (Smith et al., 2013). At this phase, a chart was made with all participant numbers, the words “yes” or “no,” and two questions: “present in one-third of sample?;” “present in one-half or more of the sample?” (Smith et al., 2013). The researchers maintained an awareness that the same super-ordinate theme could re-occur in difference themes. For example, “valuing and devaluing the body” reoccurred in both the sub-category of shape and size dimensions, symbols, and comparison of the body before HAART and after HAART. Finally, a master theme with super-ordinate themes and thematic sub-categories or areas of patterned concern for the participants was created for the sample, highlighting both similarities and distinctions with participants’ responses (Smith et al., 2013). The research team moved to

deeper levels of interpretation, using microcosmic interpretations of participants' excerpts to illuminate macrocosmic interpretations of the lived meaning of body image for REHMHA. At this phase, self-reflexive memos, journals, and bracketing were again emphasized. Where a research member(s) needed clarification, they checked in with both other team members and the participant(s).

Presentation of findings. Using the guidelines for IPA research outlined by Smith et al. (2013), results were the product of the rigorous analysis by the research team. An IPA write-up provided a full narrative account for the reader that moves systematically from one super-ordinate theme to the next with thick rich descriptions accompanied by interpretations. In order to achieve this systematic account, the result section outlines and summarizes each super-ordinate theme found during analysis. The write-up then moves sequentially from one super-ordinate theme to the next. Participant verbatim excerpts are used with varying levels of interpretative analysis examining body image for REHMHA at the microcosmic individual level and the macrocosmic group level. Where applicable for purposes of revision, the research team revisited models of maps, patterns, and original transcript and notes to examine if better descriptions could be used to capture the essence of the super-ordinate themes. As mentioned previously, a master theme table (Table 4) is presented in the appendix with each super-ordinate theme highlighted with corresponding excerpts from participants. Results from the demographic questionnaire, body image questionnaire, and PLS are also displayed in tables (see Table 1 for demographic questionnaire results; Table 2 for body image questionnaire results; Table 3 for PLS results).

Trustworthiness

Utilizing participant feedback, check-ins, and participation assisted in meeting qualitative research standards of credibility or trustworthiness (Lincoln & Guba, 2000; Morrow, 2005). In this study, trustworthiness was incorporated in the following ways: use of member checks or respondent feedback within interviews, during checking for transcription accuracy, and throughout data analysis process; use of research team members with prolonged engagement with the specific client community and are rich in diversities (e.g., disciplines, language ability, nationality, immigrant status, living with HIV, sexual identity); engagement in journal writing exercises from the beginning through the end of the study to gain greater self-awareness of bias and the potential for personal bias to manifest in the interpretation of the study; consultation with research team members through weekly research team meetings, held both virtually and on site, with utilization of group consensus at all phases of data coding and revisions; open invitation to research participants to join weekly team meetings with a calendar of times and days of open team meetings distributed to research participants; utilization of adequate data or enrollment of diverse research participants; utilization of diverse data mediums (e.g., semi-structured interview, demographic questionnaire, body image questionnaire, PLS, memo writing); maintaining an auditing trail; an anticipated distribution or sharing of results with participants in an individual meeting after dissertation defense; and an anticipated distribution or sharing of results in a community forum for individuals living with HIV/AIDS, healthcare professionals, and academic community members after the dissertation defense.

It should be noted that a total of ten participants attended open team meetings, with no more than one participant sitting in at the same time on open team meetings. As these meetings were held in the same clinical space, team members observed that participants engaged in a

similar process before entering into the meeting room. First, participants walked down the hall; next, they peered into the room window and then did not enter if an unidentified/unknown man was present. During check-ins with attendees, participants made it explicitly known that they would not feel comfortable attending the meeting if they believed another man, whom they did not identify as part of the clinic staff, was present. It should be noted that participants were encouraged to attend the open team meetings by a research team member who openly acknowledged his HIV status and was known to be an elder of sorts in the clinic community. Participants were given a projected month/year, June 2015, for when distribution or sharing of results individually and then in a community forum was anticipated to occur. Given this experience of participants attending open team meetings only if no other participant were present, it is not known if participants will attend the community forum; rather, they may prefer individual sharing of results only.

Chapter IV

Results

Demographic Questionnaire

Descriptive information for participants' demographic characteristics is shown in Table

1. These results are presented for three main areas, as shown below.

Age, disease, status, medication adherence, body weight, and height. Of the 21 participants (ages 23-67 years; mean age = 48 years), 8 had a disease status of HIV positive, and 13 had a disease status of AIDS defined, with a range of 3-33 years living with HIV or as AIDS defined (mean years living with disease = 15.7 years). Though 76.2% of participants reported taking their HIV medications as prescribed, over 52% ($n = 11$) reported missing doses of HIV medications with almost 55% of these participants missing 1-2 doses per month. Participants' body weight ranged from 128-268 pounds (mean weight = 188 pounds) with heights ranging from 5 ft 3 in – 6 ft 3 in (mean height = 5ft 8 in).

Relationship status, skin color, identity, and language. Almost 62% of participants reported their relationship status as single ($n = 13$); an additional 28% reported being married (14%; $n = 3$) or separated (14%; $n = 3$). Participants named 12 different color descriptors to define their skin color, with the most popular responses as “black” ($n = 5$), “brown” ($n = 4$), and “tan” ($n = 3$). Participants named their identity African American (14.3%; $n = 3$) or African Native (28.6%; $n = 6$); 6 individuals identified as Hispanic (all from Puerto Rico (28.6%), 2 as Latino (9.5%), 1 as Native Pacific or Hawaiian Islander, and 3 as mixed identity (14.3%). Most participants named their primary language as English (76.2%; $n = 16$) though 23.8% name their primary languages as other than English including Spanish ($n = 2$) and African languages ($n = 3$) including Akan, Luo, and Swahili. Seventy-one percent of participants named secondary

languages that included English ($n = 4$), Spanish ($n = 7$), and African languages including Ga Tsi ($n = 1$), Swahili ($n = 1$), and Yoruba ($n = 1$).

Educational level and income. Almost 10% ($n = 2$) of participants had an elementary or primary educational level; almost 43% ($n = 9$) had either some high school, a GED, or a high school diploma; almost 10% had vocational schooling ($n = 2$); 33% ($n = 7$) with some college education, and one participant had graduate coursework. Over 71% of participants were unemployed ($n = 15$) with 81% ($n = 17$) having income levels under \$20,000.

Body Image Questionnaire

The body image questionnaire covered three main areas, as shown below. Item-level responses are summarized in Table 2.

Exercise and diet. Over 52% of participants ($n = 11$) did not exercise regularly, with minutes of exercise per week ranging from 0-840 minutes ($M = 155$ min). Seventy-six percent could not afford a gym membership. Fifty-two percent ($n = 11$) reported eating a healthy and balanced diet; the almost 48% of participants ($n = 10$) who did not eat a healthy and balanced diet stated that having greater economic resources to eat three meals per day and to afford more nutrient rich food would assist them in eating a more healthful diet rich in protein/meat fruits, and vegetables.

Other medical conditions. Almost 67% ($n = 14$) of participants had other health conditions in addition to HIV. These conditions included hepatitis C, diabetes type II, heart disease, morbid obesity, osteoporosis, hyperlipidemia, hypertension, bipolar disorder, major depressive disorder, and anxiety disorders.

Cosmetic surgical procedures before and after diagnosis. No participants had any cosmetic surgical procedures before their HIV or AIDS defined diagnosis. After HIV or AIDS

defined diagnosis, 19% of participants had cosmetic surgical procedures ($n = 4$). These cosmetic procedures included liposuction for HAART induced gynecomastia, cheek implants and facial fillers for facial wasting, liposuction for HAART induced buffalo hump, and a panniculectomy for excess abdominal skin and fat from HAART. Over 76% of participants ($n = 16$) stated that they would get a cosmetic surgical procedure for areas of their body that they did not like. Identified surgical cosmetic procedures that the participant would consider if covered by insurance included: facial fillers, butt implants, calf implants, liposuction of chest and peck implants, and liposuction for excess abdominal fat. Most participants reported never using facial fillers such as Sculptra for facial wasting (95%; $n = 20$), never injecting steroids (95%; $n = 20$), did not use testosterone replacement (90.5%; $n = 19$). Almost 29% of participants reported taking dietary supplements ($n = 6$).

Tattoos and shaving. Thirty-eight percent of participants ($n = 8$) reported having tattoos with all tattoos acquired after HIV or AIDS defined diagnosis. Number of tattoos ranged from 0-27 ($M = 3.76$) with the largest percentage of participants with tattoos reporting tattoo locations on their arms and chest/abdominal region. The majority of participants, almost 67% ($n = 14$) reported shaving areas aside from their face and neck with most endorsed shaving regions as the under arms, chest, and genitals.

Perceived Lipodystrophy Scale (PLS)

Total PLS scores ranged from 0-27 with a mean total score of 10.00. Twenty out of 21 participants or 95% of participants endorsed having fat wasting or fat accumulation changes as identified by the PLS with participants endorsing either fat loss or fat accumulation for body regions and never both fat loss and fat accumulation. Fat gain in the abdominal region was most

endorsed by participants ($n = 16$), followed by fat gain in the face ($n = 10$). Detailed item-level information is presented in Table 3.

Semi-Structured Interview

Analysis of the semi-structured interview data revealed that REHMHA explored body image experiences through three super-ordinate themes: describing the valued and devalued body, losing and gaining control, and navigating social dimensions of visibility and invisibility. The first super-ordinate theme of “describing the valued and devalued body” highlights the importance of how REHMHA think about what is valued and devalued in the generalized male body and in their own bodies. REHMHA explore this super-ordinate theme through contemplating valued/devalued shape and size dimensions; use of symbolic imagery with reference to the symbolic images of the valued male body and then symbolic images of the devalued REHMHA body; and through comparison of the valued body before HIV or AIDS defined diagnosis and HAART then the devalued body after HIV or AIDS defined diagnosis and perceived HAART induced physical changes.

The second super-ordinate theme, “losing and gaining control,” refers to how REHMHA experience loss of control and seek to gain control over their feelings, perceptions, and behaviors with respect to HIV or AIDS defined status and/or physical transformations experienced post-HAART. The men experience loss of control and seek to gain control in several areas including routine activities (e.g., looking in the mirror, grooming), intimacy, use of clothing/tattooing, and how they choose to respond or engage with medical care, medical providers, and their respective communities.

Finally, the third super-ordinate theme, “navigating social dimensions of visibility and invisibility,” describes how the men understand their body image through a deeper socio-cultural

lens. It is the socio-cultural lens that assists the men in deciding how they will position themselves along a trajectory of invisibility or visibility. The super-ordinate themes and subcategories are displayed in Table 4 and represented in a diagram form in Figure 1.

Theme 1: Describing the Valued and Devalued Body

Valued/devalued shape and size dimensions. In exploring their own body image, REHMHA consistently made reference to the shape and size dimensions of the valued versus the devalued male body. REHMHA appeared to reference their own experiences of HIV, medical care, and lipodystrophy in depicting what they believed to be valued and devalued in the male physique.

P.5 opened his discussion of what would be undesirable for the male body by declaring: “Ain’t nobody want no bones.” When first discovering their HIV or AIDS diagnosis, most men reported believing that their bodies would take on the appearance of wasting with visible bones, frail frames, and hallowed cheeks. This fear of appearing as thin or as “a bag of bones” seemed to inform and serve as a reference point for what the participants thought of as constituting desirable shape and size dimensions including being “a muscly man” with a physical presence described as “big”, “bulky”, “puffy”, “pumped up,” and “strong.” Participants indicated that the detail of body parts would compliment large size including “sculptured chests,” “carved out,” or “toned, hard looking” arms and legs. For many participants, the ideal or valued shape and size also required specific dimensions. Participants valued physical height over 6 feet tall, weights over 200 pounds, waists ranging between 34 and 36 inches, and six pack abs.

Descriptions of valued and devalued physical shapes and sizes were often prefaced by the reoccurrence of the words “should,” “not,” and “no.” P.2 instructed “the legs should not be too hairy or too much without hair, they should not look like toothpicks...the body should look like

an athlete, not too skinny and not too fat...the butt should look medium, not too skinny, not too fat.” Participants also highlighted the importance of the shape of the abdominal region with prohibiting statements such as “no beer belly” and “no muffin top.” Using such figurative phrases, the men spoke of any excess flesh that did not conform to ideal shape and size as taking on a less human and objectified quality (e.g., “ain’t nobody want no bones;” “no muffin top,” “no beer belly.”). P.4 played with language as a means of describing how the body should conform to valued shape and size dimensions: “there should be no flab flopping around. If a man has to pinch an inch then it’s time to do something about that.” If “flab” could be seen “flopping,” then the physique exceeds ideal parameters. Likewise, if the flesh could be pinched or detected by the measure of touch, then the person would need to conform his physique back to valued/acceptable standards.

In using the words “should,” “not, and “no,” REHMHA started to generate a classification system to rank dimensions of the valued versus devalued body. This classification system appeared to be reflective of how participants collectively internalized and extended messages related to living with HIV or as AIDS defined, receiving medical care, and experiencing perceived body changes attributed to lipodystrophy. Many REHMHA described interactions with medical providers that echoed a similar language used in their contemplation of valued and devalued shapes and size dimensions of the male physique. The excerpts below of participants speaking about encounters with their doctors reflect a similar affirmative or prohibitory language:

P.2: I could never, ever tell my doctor that I wasn’t taking these meds all the time. He would tell me no, that I couldn’t do that. He’s like my pops [i.e., father].

P.4: Every time I get on the scale my doctor screams “no! this weight is no good. You shouldn’t be that heavy.”

P.5: Doc is about the numbers [referencing his HIV viral load], they should be what he wants them to be.

Breaking down the body into a classification system of shapes and sizes and speaking in strictly dichotomous terms of what the body should/should not look like or what it should/should not conform to, REHMHA might inhabit the role of their physicians as spectators, gazers, and judges of the acceptable/valued and unacceptable/devalued body. They might also show how REHMHA's bodily expectations intimately interact with medical care received in relationships with doctors, in the act of being weighed at a doctor's appointment, and in the routine act of getting blood work to measure HIV viral load and immune system function.

The language of "should," "not," and "no" of valued/devalued shape and size dimensions may also reflect REHMHA's reaction to a sense of physical shape and size imbalance created from HAART-induced lipodystrophy. Most men used the same language to describe how their lipodystrophic bodies were unable to regulate between extremes of "too skinny" (e.g., "legs like toothpicks;" "bones") or "too fat" (e.g., "beer belly" or "muffin top"). P.8 spoke of his struggle with physical shape and size imbalance, grappling with how his body did not meet what he envisioned for a male form:

I look at my body and it doesn't make sense...the middle of my body looks like a muffin, my arms and legs are like toothpicks, and then if you look at my face, it's a fat neck with one cheek sunked in more than the other [i.e., other cheek]. I shouldn't look like this. I should have a waist. I should have some sort of muscle on my arms and legs. A man shouldn't look like this.

Symbolic images of the valued/devalued body. REHMHA used symbolic images as another mechanism to evaluate the valued or devalued physical attributes of other men's bodies and their own bodies. In describing the ideal male physique the participants invoked symbolic images of superheroes, fantasy movie characters, or animals with attributes of dominance, strength, and stamina. In contrast, they unequivocally referenced REHMHA's sense of a

deficient and devalued physique through symbolic images that represented weakness and fragility including skeletons, rodents, and insects. Once again, the experiences of living with HIV or as AIDS defined and lipodystrophy appeared central to the men's narrative accounts of a devalued and denigrated sense of body image.

One-third of participants described the valued and idealized male physique through heroic symbolism including superheroes and muscular fantasy characters from movies as captured in the excerpts below:

P.6: An athletic, heroic body, perfectly built, lots of muscles in a heroic way. Like a Superman type of body.

P.14: To me a well-built man has muscles in his arms, and what they call these? Six packs? Did you ever see that movie *300*? All those guys had no stomachs. That's the way that men should look like, the men in that movie.

P.6 used the word "heroic" twice, connecting shape and size to a body that is "athletic," "perfectly built" with "lots of muscle." This description eventually conjured up the image of "a Superman type body." P.14 noted specific features (e.g., muscles in arms, a six pack), bridging what "men should look like" to "the men in that movie." Similar to other participants' responses, P.6's and P.14's responses blurred the lines between an achievable ideal that men can aspire to and a fictional ideal that men cannot attain (e.g., as symbolized in the body of Superman or Hollywood action heroes). Their understanding of a symbolic ideal provides important information about how they envision the physical dimensions of power with these bodies taking on almost hierarchical and moral characteristics. Whether athlete, Superman, warrior, or movie star these idealized bodies are described for their performance, display, and value.

Several participants illustrated physical ideals with animals appraised for their strength, dominance, and stamina. P.19 used animal imagery to convey his understanding of the valued male physique through a story of his uncle, a former bodybuilder:

P. 19: I got an uncle who used to be a body builder. When you are a body builder that's not really your body. It doesn't mean it's a normal body. He was building his body for competition, for the perfect shape and size. I think he was doing it to be a strong man, as strong as a bull, maybe more than that to be a dominant figure. That is the reason why my uncle was doing it because he wanted to be a strong man and dominant, like an animal, natural. Like animals, they fight to be dominant. That's a natural instinct you have, to dominate let's say if you're a man. Some men are like women because they don't try to have this shape and size of a man. Let me give you an example of an animal, a lion. That's what I think we should all try to be, a dominant man with our shape and size like my uncle. To want to look like this, this is natural. When you look like a lion, it is like you are saying: "I'm the one, that's my territory." To be like the lion, my uncle had to use steroids. You must do this to become big in shape and size.

First, P.19 described bodybuilding as a competitive vehicle to achieving a valued shape and size. He emphasized, however, that the physique of a body builder is "not a normal body" but rather the drive "to be a strong man, dominant, like an animal" as "natural." According to P.19, it is the drive to engage this physique, though not necessarily natural or obtainable, that defines the essence of being a man and consequently having a valued body image. The participant connected his uncle's pursuit of attaining the perfect shape and size to animal imagery with associative characteristics of a bull and lion that includes the descriptors: "strong," "dominant," "natural." For P.19, the shape and size of a man is interchangeable with the physical and characteristic attributes of a lion. If men do not "try" to attain this shape and size, even through artificial means (i.e., "to be like a lion, my uncle had to use steroids"), then they risk being "like women."

Other participants contrasted physical ideals with physical deficits through images symbolic of a loss of strength and a sense of diminished self. P.1 referenced ideals and then

deficits through speaking about what his legs might look like without fat wasting, a side effect he attributed to long-term use of HAART:

P.1: With all the walking I do, I should have legs like a racehorse and I do not um, my thighs are the size of some people upper arms.

The image of “legs of a racehorse” suggested toned legs with definition, musculature, and stamina. Through this symbol, P.1, set up a contrast between a physical ideal and a deficient/devalued reality; “my thighs are the size of some people’s upper arms.” P.1 did not compare his thighs exclusively to men’s upper arms but rather chose the word “people” allowing a space for women to be considered in this comparison.

P.1 introduced a second symbolic image of an emaciated Auschwitz survivor to describe other physical effects of his long-term use of HIV medications and his integration of this image into his own self-perception:

P.1: People that have known me for years told me I look like an Auschwitz survivor.

I: How did you react to that?

P.1: What can you say? I do look like one. They saw the dramatic weight loss and such. So did I.

Using the symbol of the Auschwitz survivor, P.1 noted the importance of the how his appearance was perceived by others, what his body communicated to others. He accepted this symbol as representative of his body when he rhetorically questioned then stated: “What can you say? I do look like one.”

Similarly, other participants told of coming to grips with a devalued body through images of a tortoise, guinea pig, skeletons, and flies. P.12 noted that after taking HAART his body, in form and movement, resembled a tortoise: “I have this wide back, scaly skin, double chin, and this stomach that just hangs. My body looks slow. It feels slow.” The participant pointed not

only to devaluation in physical shape and size change as evidenced through his description of a “double chin” and “this stomach that just hangs” but also through negative changes in his skin texture (i.e., “scaly skin”) and carrying a body that both “looks slow” and “feels slow.” This participant evaluated his body through not only shape and size dimensions but also through other physical signs such as skin appearance and movement.

P.8 contrasted his experience of taking HAART to friends who elected not to take HAART. Recalling his body after one year of taking HAART, he noted: “I felt like each part of my body was a different size. It didn’t match. I felt like a guinea pig.” The participant recalled how other friends, with whom he had used drugs with in the past, did not take HAART and transitioned from “walking skeletons” to “dropping dead like flies.”

Using symbols the men compared the ideal male physique with their lived perceptual reality. These symbols seemed to create a system of hierarchy and classification moving from valued bodies represented for their fantastical shape and size as captured by superheroes, Greek warriors, and lions and descending to participants’ own devalued bodies as depicted by the Holocaust survivor, insects, rodents, and skeletons. The symbols move from images of vitality, virility, strength, and life to weakness, slowing, pestilence, decay, and death. They might also inform how REHMHA created and categorized the valued/devalued male body in shape and size dimensions (e.g., “Ain’t nobody want no bones” versus the “muscly man” with a “big”, “bulky, “puffy,” “pumped up,” and “strong” physical presence).

Comparison of the valued body before HAART and devalued body after HAART.

REHMHA expressed the most body satisfaction and valuing of their body before HAART as compared to after HAART. REHMHA’s sense of body satisfaction before HAART included valuing the shape/size dimensions of their bodies and experiencing their bodies within valued

socio-environmental, systemic, and cultural frameworks. After HAART, most REHMHA reported dissatisfaction with a pattern of HAART-induced physical changes and no longer referenced the socio-environmental, systemic, or culturally contexts that seemed to give their bodies both value and meaning.

Before HAART. P.20, for example, expressed greatest body satisfaction in the physical activity of dancing and with peers in a 12-step recovery program:

P.20: Uh that was in 2005 or 2006, before I was diagnosed. I was at 200 pounds or a little under. I had definition. I wasn't using. I used to go out and dance. I was in ____ [name of 12-step recovery program]. I used to go out with dancing groups, people who tried to stay clean. And they danced and I was like 'alright, alright, let's go, let's go, let's go.' I was taking care of myself all around even going to the gym.

P.20 explicitly located his best body before his HIV diagnosis and at 200 pounds. He then discussed the framework for this experience that included: abstinence from substances, socialization in the recovery community, and the behavioral/physical activities of dancing and going to the gym. These behaviors involved movement and a high energy level as emphasized by his declaration: "alright, alright, let's go, let's go, let's go." He referenced experiencing a holistic sense of self-care: "I was taking care of myself all around."

Several participants spoke of being most satisfied with their bodies in the context of systems including prison, the military, and organized sports. These participants spoke of their bodies as extensions of the systems' distinct cultures and structures. Participants with incarceration histories acknowledged the sense of pride and achievement gained through daily routine, increasing size/shape dimensions, and competition.

P.21: I was on a power lifting team. I held the record for my size and my weight for ____ [number of years]. This was in the state penitentiary. A power lifting team is when they compete and have competitions against other places. You have to work out 5 days a week and work hard to gain strength. I was working out two times a day for two hours, in the mornings and in the afternoons.

P.2: Yes it was when I was in the penitentiary. I was very big, very built, muscly, muscle man. I did ____ [number of years] in the penitentiary. I was big. My exercise was different. I did my exercise everyday. I did calisthenics, handball, and I also lifted weights, pull-ups push-ups. That was when my body was at its best. I weighed 230 pounds. It was a lot of weight but it was all muscle.

Both P.21 and P.2 located their best bodies in the context of serving time and resultant behavioral activity. Additionally, they focused on size, holding a record for size/shape dimensions or the perception/noticing of size/shape dimensions: “I was very big, very built, muscly, muscle man.” They also appeared to think about this ideal in comparative terms or having bodies that could be compared to other men for confirmation of their ideal. A body of larger shape and size dimensions provided these participants with self-protection from violence against other men. As P.17 recalled, “you wanted to stay fit because of the danger. If you’re not strong, you’re a target.” Post HIV and HAART, these same participants reported a weakened and vulnerable physical and emotional self. Thus, it made sense that these men would express most body satisfaction in a period of their lives where they felt as if their bodies could protect them.

Another system mentioned as being an important context for experiencing body satisfaction before HIV/AIDS and HAART was the military. P.9, a past member of the military, recalled his best body as an extension of military training:

My body looked like someone in the military. I was 22 years old and in training — swimming, long distance running, lifting weights. I had 1% body fat. My body showed my routine. I felt proud.

P. 9’s most valued body occurred within concrete behaviors grounded in physical prowess and the execution of tasks. The percentage of body fat, 1%, stood for behavior, an exemplification of routine with a resultant feeling of pride in having a body that visually spoke for itself.

Other men remembered having most body satisfaction in the context of organized sports and before HIV diagnosis and HAART. P.10 won an athletic scholarship at a university. Although proud of his educational accomplishment as the first in his family to attend university, he reiterated that he felt the most pride from having a body with more skill, ability, and definition compared to other men his age:

My body could do things that most boys my age couldn't do. I had a body most boys my age didn't have. I knew it. I was a top ___[name of sport] player at ___, so I was always training, lifting weights, squats, running, pretty much a full workout. I played basketball 3-4 hours a day. My arms were big, my chest was tight, my legs were bigger, my butt. Everything was bigger and firm because I was in good shape. Not like now.

Like participants 21, 2, and 9, P.10 highlighted the importance of intense physical exercise to achieve his perceptually best body shape and size dimensions. All participants displayed their bodies on the metaphoric stages of the systems/institutions they belonged to --- prison, the military, and the basketball court. In the act of performance their bodies became symbolic, deemed worthy, and confirmed through the gaze of others. Their bodies also held the possibility of being used as a weapon against other men, in being able to “do things most boys my age couldn't do,” in having a body that shares a symbiotic relationship with war, in gaining strength/muscle for the unpredictable violence of incarceration. Finally, in their use of the past tense, in remembering these ideals as a distant memory, or in a pronounced shift in their sense of self (e.g., “not like now”), the participants established a baseline for telling the stories of their bodies' decline.

After HAART. Speaking of their bodies after HAART, most REHMHA reported body dissatisfaction related to three categories of HAART induced physical transformation: fat loss, fat gain, and an inability to build muscle; changes in veins, skin, and hair; and changes in movement. Most REHMHA also appeared to stop participating or enjoying the socio-

environmental, systemic, or culturally contexts that seemed to give their bodies both value and meaning before HAART.

Two participants, P.18 and P.14, exemplified the most commonly reported lipodystrophic changes of fat gain, mixture of fat gain and fat loss, and an inability to build muscle mass reported by the sample:

P.18 [speaking of fat gain and inability to build muscle mass]: I was taking the medication for about six months when I stepped on the scale at the doctors office, 30 pounds heavier, all in my gut and chin. I was lifting weights and my arms lost all their muscle. I went from a man to looking like a fat boy.

P.14: I gained fat where I didn't want it and now no muscles where I want them. It's fat though not muscles, fat sloppy.

I: Could you tell me more about what specific regions of your body you gained and lost it?

P.14: My stomach and neck are fat...my arms and legs no muscles, just small and fat sloppy. Now I'm this fat puny thing... like what do you call it? An oompa loompa.

Both men clearly conveyed how they believe their shape and size to be affected post-HAART.

They also suggested a loss of control over their shape and size. For example, P.18 lifted weights with the intention of maintaining the muscle in his arms and only lost the muscle in his arms.

P.14's body could not gain fat and muscles in specific regions of his body where he wanted to see more fat and muscle. With size and shape changes, both men selected words that spoke to their body dissatisfaction: transitioning from "a man" to a "fat boy" and morphing into a "fat puny thing,...an oompa loompa."

Another area generating body dissatisfaction post HAART included the appearance of thick, bulky veins, skin rashes, and hair loss. P.21 contrasted his muscular legs pre-HAART and during incarceration with the thick bulky veins and fat loss post-HAART: "My legs just went from strong and big to lumpy with black and blue veins. It's something I hate and live with.

This is what the medicine looks like.” P.21 viewed medication as being worn on his body with a shift in his physical ideal of “strong and big” to “lumpy with black and blue veins.” P.21 depersonalized these changes and simultaneously acknowledged that they were forcibly part of his experience. He objectified these changes as reflected in his word choice of “it’s” and “this.”

Some participants complained of non-specific and specific restrictions in their movement post-HARRT leading to body dissatisfaction. As noted in a previous section, P.12 reported concrete physical changes (e.g., scaly skin, a double chin, a wide back, and a hanging stomach) that impacted perception of energy and movement. There was a sense that P.12 felt entrapped and limited by his slowed body.

The participant most affected by HAART-induced mobility restrictions and HAART-induced wasting syndrome was P.13, the youngest participant at age 23, congenitally infected with HIV, P.13 was only tested for HIV after his mother died of AIDS related complications, her status unknown to the family until her death. In the first 8 years of his life, before discovering his AIDS defined status, and taking HAART, he remembered himself as a fat child who loved to eat. At age 13, he experienced antiretroviral toxic neuropathy, a neurological complication of HAART, permanently restricting both his mobility, potential to exercise:

It limits me a lot. I used to walk two miles to school and now I can’t even walk a half-mile without sitting down. My brother and me used to run together. He says to me “I wish your life would be better. I want the old munch back.” I’m like ‘yeah so do I’ because he was incarcerated. He went to jail and I was fine. He came back years later and I’m like this. He literally has to carry me up the stairs.

He told of his transitioning from bodily satisfaction before HAART to bodily dissatisfaction after antiretroviral toxic neuropathy through comparison— walking two miles to being unable to walk a half-mile without rest, running with his brother to needing to be carried up the steps by his brother, being a fat child to a young adult whose body as affected by HAART

bears a frail frame, wasted limbs, and walks with braces or uses a wheelchair on his most difficult days.

Theme 2: Losing and Gaining Control

As a reaction to HIV or AIDS defined diagnosis and perceived or projected physical changes as a result of HIV or AIDS defined diagnosis and/or taking HAART, REHMHA reacted to feelings of loss of control over their bodies with a range of concerted efforts to regain control.

Routine activities. Some participants reported loss of control in daily grooming activities and bodily processes as a result of the physical effects of lipodystrophy. P.11 described the emotional and physical pain in the routine activity of looking in the mirror and shaving facial hair:

I look in the mirror to shave and I see this face that's sunken in and doesn't look like it's mine. It's hard to look in the mirror. My razor gets caught in the spaces in my face. I always end up bleeding...My blood reminds me of how contagious I am. Then the cuts, they don't heal right. If I didn't have to shave, I won't look in the mirror.

P.11 preferred not to look in the mirror as he saw a “face that's sunken in” and one that he did not recognize as his own. With facial wasting, his razor got caught in the grooves of his face with an inability to control his skin from getting cut, from bleeding, or from proper healing because of his immune suppression. The sight of his blood reminded him of both living as AIDS defined and his contagiousness, another aspect of experiencing his body as out of control. Despite the physical pain and complications, P.11 still chose to shave his facial hair though he conceptualized shaving as something that he had no choice in doing (i.e., “if I didn't have to shave.”).

Other participants made concerted efforts not to look at their physical transformations below the neck, attempting to control for the physical transformations that they did not want to

see. They described the act of having to see/view their bodies as traumatic. Suffering from HAART-induced abdominal fat accumulation, gynecomastia or fat accumulation of the breasts, and type II diabetes complications, P.14 refused to look in a full-length body mirror. Like P.14, individuals with lipodystrophy and HIV have a five to nine fold increased risk for developing type II diabetes (Kaira, Kaira, Agrawal, & Unnikrisnan, 2011). For over 15 years, P.14 used only the mirror in his medicine cabinet to guide the shaving of his face and neck. Hospitalized after a foot amputation, he looked into a full-length mirror for the first time:

Like a month ago, I saw my stomach and these big titties in the mirror for the first time. ‘Are these really mine?’ I looked like a fat woman.And then no foot. Right away when I saw this I thought, you’re gonna die. I really felt like I was gonna die. I went to my bed and started to cry. I never cry. I felt so depressed that I even talked to the nurse [identified in the later part of the interview as a female].

P.14 spoke of the effects of HAART as creating a body out of control with fat accumulation in the stomach and chest (e.g., noted by the word choice “big titties”), an amputated foot, restricted mobility, and a fear of death. This sense of being out of control extended to how he perceived the appearance of his body: “I looked like a fat woman.” P.14 also lost control of his emotional state. Although he “never cries,” he confessed that he “started to cry” and “even” talked to the female nurse, a vulnerability that he, later in the interview, related was something that he would never otherwise show.

Intimacy. The appearance and stigma from HAART-related physical changes and HIV or AIDS defined status left 19 of the 21 participants to report intentionally not engaging in sex, limiting sex or acts of intimacy, and/or refusing to be touched. Shortly after starting HAART, P.5 noticed hyperpigmentation of his nails and skin. A discoloration of skin and nails symbolized his stigmatized status: “it reminds me that I’m contagious.” After a two-year relationship, P.5 refused to have sex with his partner or kiss his partner on the mouth. P.5

highlighted both his powerlessness and attempt to reassert power through dominance and physical control in his relationship:

I'm mad at myself. Because I knew this shit was out there and I didn't take the precautions. It's pride, embarrassment, shame, fear. I don't put no curbs on my life other than sex and touching. I got to consider that I got to deal with things that's unfortunate, take it, roll with the punches. I'm not gonna get anyone else sick besides me. And whatever else happens happens cuz you can't change a damn thing. So um, my dad always told me "I don't care what it is, if you digging a ditch, be the best damn ditch digger in the world." And I always listened to him. You don't want to be there but damn it if you done then go ahead and do the best you can do. And that's the way I was raised. So I will be the best with HIV that I can and that means no sex, no kissin.

P.5 indicated that he felt "mad at himself" for losing control, for becoming HIV positive. He admitted to a mixture of "pride, embarrassment, shame, and fear" for allowing himself to be imperfect, vulnerable. He connected sex and even kissing as having the potential to infect others (i.e., "I'm not gonna get anyone else sick besides me"). In all other facets of his life, he did not restrict himself or placed "no curbs on my life." A sense of fatalism pervaded his understanding of diagnosis. Through the image of the laborious body of the ditch digger, he associated his diagnosis both to the male body under duress and to the wisdom of his father. Being "the best damn" man living with HIV might imply protection of his partner and regaining a sense of control over his body's potential to be contagious. P.5 refused to take into account his partner's desire for sex and intimacy, stating later in the interview: "I don't care what she thinks...it's something that I've got to do."

REMHMA's self-perception of lipodystrophic changes or uncertainty of how these changes could be perceived by their partners occasioned several participants to report limiting sex or acts of intimacy:

P.7: How should I say this, what I want to say here? Hmm...when my stomach looks so fat that I can't see my thing [points to his genital region], you don't want to have sex...I try to get out of it as much as possible.

P.10: I used to have bigger arms and well...like I said before they don't look like at all what they used to be. [Name of partner] has bigger arms than me...I find myself making excuses...trying to get out of hugging her...trying to get out of having sex with her cuz' I don't look right holding her with these arms...I look at them sometimes and they make me disgusted...they must make her feel that way too.

Both the diagnosis of being HIV or as AIDS defined and/or HAART-related physical changes led to an overall sense of isolation, feeling different, and being hurt by or rejecting of the touch of others, including partners and family members. P.2 (Hispanic, Puerto Rican) reported that the fat wasting in his arms and buttocks made it painful to be hugged by his partner and family members. Fat wasting in his buttocks made extended periods of sitting down to cuddle with his partner painful— something that he used to enjoy before experiencing: “I took my doctors suggestion to wear padded underwear or put a pillow underneath my butt if I wanted to sit on the couch to cuddle with [name of partner]...It didn't work. I was still in pain.” The pain and an inability to prevent pain eventually led to the participant's attempt to avoid or limit hugging and cuddling.

P.13 spoke about profound feelings of separation from parents (by death), his non-HIV positive siblings (by disease status), peers (comparing his body to their bodies), other REHMHA (due to participant's transmission route of being congenitally infected) leading to his rejection of being touched:

I don't like being touched period. I don't like people touching me...like I yell at people 'don't touch me'...It's just. I don't know....I'm so different. I don't want to be. No one can understand me.

In this short excerpt, the participant used the word “I” seven times, “me,” three times, and “don't” five times. With these words rhythmic repetition and the participant's admission that he

yelled at people not to touch him, he suggested a desire for agency, control, ownership, and created a purposeful separation of his body from “touching” by others. It also appeared to be connected to his loneliness and isolation in not being understood: “no one can understand me.”

Use of clothing and tattoos. As a reaction to uncontrollable physical alterations, many REHMHA sought to gain control of their bodies or the perception of their bodies by others through wearing clothing to mask/hide symptoms of lipodystrophy or through the targeted placement of tattoos on their bodies. P.16 called the fat accumulation in his abdomen “a complete embarrassment.” Using clothing as a cover, P.16 veiled the appearance of fat accumulation and thus protected his AIDS defined status:

They’ll know. They’ll know and I’ll be rejected. I don’t talk about my body to no one. I just hide it. I wear a lot more baggy clothes since this medicine to hide my body so you can’t notice the AIDS. It’s like when women wear a dress from head to toe. They’re ashamed. Most people who are fat cover their body. Most people who don’t look good cover their body.

The excerpt shows the tension between what P.16 believed he was able to control (i.e., the appearance of fat accumulation) and what he cannot control (e.g., categorization with other subordinate groups including fully covered women, individuals who are fat, and a general category of people who “don’t look good”). Baggy clothing became akin to a suit of armor, delineating a barrier between the known and unknown, belonging and rejection. Like P.14, P.16 connected his appearance to large female size/shape dimensions (“big titties” versus “women who wear a dress from head to toe”). P.16 used the word “AIDS” suggesting that he did not connect AIDS to fat loss and wasting but rather fat accumulation. Covered with baggy clothing, P.16 seemed to protect his body, controlling how it could be seen.

Several African American, mixed identity, and Puerto Rican participants used the targeted placement of tattoos on lipodystrophic regions to regain power over how their body

would be gazed upon. P.20, for example, identified tattooing as an act of protest and control over how his body might be perceived:

P.20: Most of my tattoos are after my diagnosis. After I was taking my meds, I went to [name of beach] and my stomach was starting to stick out really bad. And I was like ‘look at my tattoos, that’s what you can look at.’

P.20 got 23 out of 24 tattoos after diagnosis. Without a t-shirt, P.20 unveiled his stomach and fat accumulation. His tattoos gave the potential viewer an opportunity to redirect their gaze. When he declared: “look at my tattoos, that’s what you can look at,” he did so with a challenging tone. There was a sense that P.20, like P.16, identified his fat accumulation with HIV status. P.20’s declaration could be interpreted on several levels. P.20 might try to engage the gazer of his body with the refrain “look at my tattoos, that’s what you can look at.” P.20 might also use his tattoos to intentionally distract the viewer from connecting his body to his HIV status. The viewer might look at his abdominal fat accumulation but then shift visual focus to the participant’s tattoos.

Engagement with medical care and the community. African Native participants sought to gain control of their bodies through adherence to HAART and compliance with select medical advice of their providers. When speaking about his body before HAART, P.7 underscored the importance of a man providing for his family as cultural benchmark of masculinity: “In our African tradition, it’s the men who are supposed to provide for the family...If you don’t feed your family, you’re not a man, that’s what we consider in our culture.” Like P.7, other African Native participants believed that the act of providing for one’s family necessitated the practice of specific actions of self-care in health care including: dedication to HAART adherence, attendance of doctor’s appointments, and checking in with the doctor concerning potential visual indicators of HIV status.

These men also feared that failure to adhere to HAART would allow their HIV status to become visible. They associated non-HAART adherence with weight loss and thought deeply about how communal knowledge of their HIV status could bring shame to their families, affect their ability to financially provide for their families, and ostracize them from their cultural communities.

P.15: If I didn't take these pills people would surely know and um there would be lots of different things that happen. I probably would lose my work. My family would be out of the community. My family wouldn't eat. People only know AIDS and that means skinny, that's death. It is shameful not to belong to your community.

P.15 made an immediate connection between taking medication, thin appearance, and being branded as having AIDS. The interpretation of his body could have compounded consequences including loss of work, the shunning of his family from the community, and fear that his family would not be able to eat. An undocumented immigrant, P.15, relied upon community members for work. Thus, his association with medication non-adherence and weight loss could jeopardize his access to community resources and ultimately his family's survival.

P.3 described the importance of not only adhering to HAART but also controlling the public perception of his health status through physical engagement with younger men in his community.

I follow every instructions every drug that the doctor gives me. You see me. I'm very fit. I'm very strong. I'm not skinny. The HIV does not make me weak. Sometimes I exercise with our teenagers from 18-25. I run more than them. I'm stronger than them. When they ask my age, I just pretend to be on their level because I don't want to explain myself, to answer so many questions. So when they ask my age and they say they are 25, I just say I'm 26. Because I don't want to say that I am 45 when I can run more than them. I can do so many things that they cannot do. The things I can lift, they cannot lift them. And I can see them by the age of 45, they will lose more strength. Even the way they walk, it is not manly.

P.3's engagement with the youngest men in his community had several potential functions. It might allow for him to control for the way he was perceived. If he was running more or lifting more than the young men in his community, he might gain additional reassurance that his body was not being interpreted as frail, sick, or weak. Asserting that he could pass for men 20 years his junior might give him further confidence that he could hide other aspects of himself such as his HIV status. In proving that he was physically stronger, despite his HIV status, he suggested that he was a real man. He subordinated other men through feminizing their behavior: "even the way they walk, it is not manly" Perhaps, by competing against other men he depicted as weak, who cannot even walk as men, he concurrently reflected both his loss of control and desire to gain control.

Non-African Native men in the sample sought to gain control and agency of their bodies and lives through a spectrum of risk behaviors. These participants connected their HIV or AIDS defined status and perceived physical changes with feelings of depression, anxiety, and stigma. P.17 elected not to take medications for the first 9 years of his diagnosis. With the arrival of HAART, P.17 decided to "give the meds a chance." When he looked in the mirror and saw a body marked by disproportionate fat gain and fat wasting, he stated he was intent on committing suicide:

I decided I would get in the car and get in an accident to kill myself...I wasn't worth anything as a man. I got a horrible body. I have a horrible body. I was no good to society. I was just an outcast. I didn't want to depend on medication... Sometimes I wondered if my doctor would think it was worth living if he looked like this?

P.17 connected his behaviors to a denigration of his masculinity: "I wasn't worth anything as a man." Unable to control the appearance of his body, with a sense of being "no good to society" and self-labeled as an "outcast," P.17 thought of suicide as an act of agency and control. Shortly

after a failed suicide attempt, P.17 met his wife, who is also AIDS defined. This relationship gave him a renewed sense of meaning, security, and purpose. However, his final question suggested a profound disconnect with the way a provider and patient may view quality of life. HAART may control the HIV virus but it may also make REHMHA feel not in control of their emotions, bodies, and lives.

Some participants expressed greater control over their bodies when they engaged in behaviors that deviated from medical advice. Recently recovering from open-heart surgery, P.4 continued with a physical exercise regimen that jeopardized his healing:

My body already looks like a sagging mess from these medications. I'm trying to avoid even more sagging so I do my push ups and curls. The doctor says that if that cage opens back up then they have to reopen me. And I just tell him 'yes' and then keep doing my push-ups and curls.

For P.4 the potential for “more sagging” outweighed the threat of physical consequences, even a second operation. It was uncertain how P.4's HIV status affected his assessment of risk. Like P.17, P.4 may have anticipated a discrepancy between his medical provider's goal (e.g., healing from surgery) and his goal (e.g., to “avoid even more sagging”). Instead of directly engaging his provider with conversation, P.4 feigned acquiescence (i.e., “I just tell him yes”) and directed his own behavior.

Participants also admitted to intentionally deviating from medical advice concerning their weight. Most men felt their doctors did not understand their dilemma of balancing weight loss and weight gain. The men thought about their weight loss or weight gain through the lens of their communities and the fear of the translatability of their bodies. P.21's (Hispanic, Puerto Rican) experience represented the experience of the majority of participants in the sample:

If I go by my doctor, I'm definitely obese. But me, my ideal weight would be 180. My doctor says I should be 160. There is a fear of looking sick if I'm too fat or too skinny. My doctor doesn't get this.

Participants attempted to regain control of their weight through monitoring their lab work and taking medication breaks from HAART. Most participants stated that they took medication breaks or reduced adherence with the intent of reducing HAART-related physical changes. Participants believed that during these “medication holidays” (P.1), they could lose weight, gain muscle mass, and/or gain fat in targeted areas of their body. Still, many acknowledged that experienced change would be temporary, as they would inevitable have to adhere to the medications to prevent further HIV-related complications or face the possibility that they would build resistance to a medication that had worked to suppress their viral load for years:

P.12: I know for a fact that these medications stop me from getting muscle... I stop them to get my muscle back, to get rid of a little of this [looks down at abdomen] and to get rid of a little of this fat here [touches chin]...I know that I can't do this forever...Like I used to be able to take [names two medications] and now I'm resistant so I got to watch with this one a little more.

P.21: I've had my doctors deny what these medications do. That's ok. I know cuz' I live with me. I know that when I started taking them, my body got destroyed...I know when I stop taking them for a week or two, I lose a few pounds, but then I've got to start them again.

I: How often do you stop and the start your medications like that?

P.21: Let me think [long pause]. About 4 times a year, one time each season.

Participants felt that they could not have conversations with their providers about stopping their medications. P.21 mentioned the denial of his doctors about his physical side effects. They also, however, feared loss of their medical and social services as P.12 (African American) explained: “if I told my doctor what I did, then not only would he know but then my case manager would know too.” Doctors knowing, therefore, could either limit or enhance access to resources. These participants described experiences whereby their medical doctors, all

of whom were men, had authority over their bodies. In addition, they felt loss of control in how their medical information would be handled, potentially reaching other members of an integrated care team and changing how they might be able to meet their basic needs.

Theme 3: Navigating Social Dimensions of Visibility and Invisibility

The super-ordinate theme of “navigating social dimensions of visibility and invisibility” captures how participants’ understood their bodies in relation to other socio-cultural contexts and consequently navigated social dimensions of visibility and invisibility. REHMHA had several areas of particular concern informing their navigation of visibility and invisibility. These included: thinking about their bodies in relation to representation of HIV positive heterosexual men in the media; thinking about social interpretations of their bodies, more specifically in relation to work; and comparing REHMHA’s collective sense of invisibility and marginalization with visibility and collective advocacy of HIV positive or AIDS defined gay men.

Media representations. When discussing representations of HIV positive or AIDS defined heterosexual men in the media, participants either were quickly able to name Magic Johnson or could not name any HIV positive or AIDS defined heterosexual men. P. 16 best summarized the response of the group by asking “Who else is there but Magic Johnson?”.

Participants used the social representation of Magic Johnson’s HIV status and body to either connect or demarcate the boundaries between his experience and their experiences.

All but three participants definitively separated their experiences from Magic Johnson’s experience. P.2’s response was most representative of these participants:

P.2: He looks normal to me. I think he’s cured...If he does have it, I would want to know how he looked that way. Are they the same medications I’m getting? I’m sure his medications cost a lot more.

First P.2 suggested that a diagnosis of HIV/AIDS necessitated the inverse of appearing normal or taking on a visual quality of abnormality. Next, P.2 considered that Magic Johnson might have been HIV positive in the past but not presently: “I think he’s cured.” With an emphasis on the word “if,” he questioned the similarities between his medications and Magic Johnson’s medications. Finally, he mentioned how socio-economic status may allow for the taking of different medications without noticeable side effects: “Are they the same medications I’m getting? I’m sure his medications cost a lot more.”

Only one participant, P.9, viewed Magic Johnson’s representation in the media positively, highlighting the importance of shared experience:

I got my diagnosis around the same time as Magic Johnson. And that helped motivate me to stay alive. I thought he might be getting bigger too cuz of the medications. It helped me.

P.9 noted the importance of being diagnosed around the same timeframe as Magic Johnson. Suffering from severe weight gain and fat accumulation, P.9 also indicated the possibility of a shared medication experience: “I thought he might be getting bigger too cuz of the medications.” This interpretation of Magic Johnson’s appearance was not congruent with the interpretation of P.2. P.9, therefore, embraced Magic Johnson as a representative of both his experience of diagnosis and HIV management.

Two participants cited Magic Johnson’s public HIV disclosure as a reason why more REHMHA do not disclose their status consequently minimizing their media representation:

P. 20: We don’t want to feel belittled like Magic Johnson.

P.19: Magic Johnson is the stigma that I’m talking about. That’s the fear of everybody. People were fearing to touch him. They said “we don’t want to play with you.” That’s the same thing. That’s why there’s none of us talking about it.

We don't want people to act with prejudice against us, fearing that we will contaminate them if we touch them.

P.20 and P.19 discussed REHMHA invisibility or non-representation in the media as a protective factor buffering against marginalization, stigma, and prejudice. P.19 connected public HIV status disclosure with having a body that could be interpreted as dangerous, a threat "fearing that we will contaminate them if we touch them." Both participants used pronouns to approximate and separate themselves from Magic Johnson, non-HIV positive individuals, and a collective we/us. Magic Johnson's experience of belittlement could become the reality of "we" with disclosure. "The fear of everybody," the fear of contamination that Magic Johnson experienced could become another reality with disclosure. P.19 labeled Magic Johnson as the personification of stigma: "Magic Johnson is the stigma that I'm talking about." The participants delineated the boundaries between "everybody/them" "we"/"us" and Magic Johnson.

Interpretations of REHMHA's bodies. P.18, who works as a manual laborer, spoke about how co-workers used the word "AIDS," to discredit another man's ability to labor.

I hear the word AIDS a lot in my business... "That guy doesn't work hard, look at his body, he must have AIDS" or "Don't touch that one, he looks like he has AIDS." They don't know the difference between HIV and AIDS. They say such stupid shit...and that's all you need is the rumor mill. You can't have that stick to you cuz then you'll get no work. They'll be black balling you from work because they will think that you're contagious and that your body is no good anyway...I stay as far away from those conversations as possible...I try to make it so they don't see me making any noise as much as possible. Sometimes that means just going along with it by not saying anything or laughing so I don't stand out.

P.18 linked AIDS to social interpretations of work ethic, health/illness, threat/contagion, and employment/financial security. P.18 was aware of the stigmatizing and detrimental

repercussions that being labeled with “AIDS” by his co-workers could have on this life, including loss of his job and economic viability. As such, he chose to “stay far away from those conversations” and not make “noise.” In order to remain invisible or non-suspect, he decided to “go along with it.” His silence and laughter could be interpreted as simultaneously active and passive.

Most REHMHA believed that the general public thought REHMHA did not work and negatively interpreted the ability and utility of their bodies. P.1 acknowledged the lack of social value placed on REHMHA’s bodies and how REHMHA, themselves, possibly contribute to the perpetuation of this image:

The general perception is that we are drug addicts or worthless bums really. And we have our body image hang ups. People have their preconceived notions based on severe lack of information and want verification about the way they feel based on severe lack of knowledge about this virus.

P.1 suggested that his “body image hang ups” contribute to rather than detract from the perpetuation of misinformation. It is uncertain what the participant views as the effect of these “body image hangs ups” leaving open multiple possibilities for interpretation including “body image hang-ups” as part of a process of self-stigmatization and failure to see the self as an agent to change these “preconceived notions.”

Other participants listened to stigmatizing conversations about their bodies but did not say anything for fear of being perceived as HIV positive:

P.11: ...You know sometimes it happens to me sometimes, people talk about us without them knowing that I have it, so I know what they have to say, you know, so usually most of the time it’s negative comments like we’re ugly, dying, lazy, dirty. I just listen.

Similar to P.18’s admission of “not saying anything” in conversations related to the disease status of his co-workers, P.11 chose to pass as a non-HIV positive man and did

this by positioning himself as a listener or observer. Later in the interview, P.11 implied that the act of listening could have internalizing consequences: “I try not to think of my body like that but sometimes it gets in my head and I think it must be true.”

The visibility of HIV positive or AIDS defined gay men. Whereas participants thought REHMHA did nothing to change the social perception of their bodies, they admired and believed that gay HIV positive men changed perception through purposeful visibility and advocacy. Participants noted HIV positive or AIDS defined gay men’s visibility in their communities:

P.1: They are at every AIDS walk and have been since I was diagnosed in ’84.

P.12: [names of outreach workers he states are openly gay and HIV positive] pass out condoms in my neighborhood. I admire that.

P.20: The first men that I met in NA were out about it [HIV positive status] were gay...They told their stories in the rooms when I would just sit there, know my secret and say nothing.

In the hospital clinic:

P.18: They are the only people that I’ve seen that come to [name of hospital clinic] and don’t hide. It’s respected.

P.6: _____[name of case manager] is gay and talks about his diagnosis with me. That is the first man that I’d seen do that. He tested me when I was diagnosed...Got me medications when I thought I’d die.

The visibility of gay men in their communities, hospital clinic, and lives seemed to be connected to other positive attitudes about gay HIV or AIDS defined men. Several participants saw HIV positive or AIDS defined gay men’s bodies as more respected, accepted, and socially useful as perhaps best represented by P.5’s response:

Everyone knows that the gay positive men are the hardest workers. They are off the hook. They work better than us. They are out there fighting the cause. We don’t do nothing. They have a fighting spirit, energy, strong, and can take care of

themselves. And you got to be able to throw down to beat one of them guys. I ain't never seen one that couldn't take care of themselves.

P.5 twice used the phrase “take care of” as a contrast for what he perceives REHMHA do not do. Through a language of comparison, P. 5 asserted that gay HIV positive men both work and advocate better than REHMHA. The depiction of gay HIV positive men “fighting the cause” suggested group mobilization and organization. This set a contrast to the group of “we” depicted as unified by what they do not do or do to a lesser degree than gay HIV positive men. Despite admiring or even feeling inspired by HIV positive or AIDS defined gay men, participants made it clear that they would stay invisible and remain marginalized.

Chapter V

Discussion

Three super-ordinate themes resulted from the exploration of body image for the 21 REHMHA participants of the present study: “describing the valued and devalued body,” “losing and gaining control,” and “navigating social dimensions of visibility and invisibility.” Within these super-ordinate themes, both HIV and/or AIDS defined status and physical transformations attributed to HAART-induced lipodystrophy were integral in how participants narrated, explored, and understood their body image. Body image may be an especially complex and multilayered construct for PLWHA (Chapman, 1998), with no universal accepted way of how it should be measured (Tate & George, 2001). The following discussion section examines key points related to the three super-ordinate themes with implications and potential interventions discussed where applicable. In addition, the discussion includes references to existent literature and select theoretical concepts.

The majority of participants expressed high levels of shape and size dissatisfaction, made especially apparent by the contrast between how participants spoke about what would be valued in the male body and then what they devalued in their own bodies. For example, their expressed fears of wasting syndrome or taking on the look of “bones” or of an “oompa loompa” set a complete contrast for what they would value in a male body — a mesomorphic body type (McCreary et al., 2005) and larger than life proportions (Leit et al., 2000). When participants spoke of what was devalued in the body, they unequivocally referenced their own perceptual deficits through the lens of HIV and lipodystrophy related experiences. Devalued descriptions seemed to be influenced by word choice reflective of their disease/medical encounters, the

physical ambiguity and imbalance created from lipodystrophy, and areas of the body rated as particularly problematic on the Perceived Lipodystrophy Scale (PLS).

In this sample, fat accumulation of the abdomen was rated as the most problematic bodily region on the PLS and was cited in REHMHA's description of valued/devalued shape and size dimensions and prohibitory statements such as "no beer belly" and "no muffin top." This finding is consistent with Huang et al. (2006) who found, for a sample of 110 HIV positive men whose sexual orientation was identified as "men who have sex with men" or "not men who have sex with men", that fat accumulation in the abdomen caused specific distress and was associated with negative effect on body image quality of life. Of note is the difference between the current study and Huang et al. in terms of the racial/ethnic identity of participants. In Huang et al., racial/ethnic identities were collapsed into the categories of "Caucasian" and "non Caucasian"; further, Huang et al. noted that those of "Caucasian race" had greater effects of negative body image on quality of life. All participants of the current study identified as racial and ethnic minorities and demonstrated profound dissatisfaction with their body image quality of life through semi-structured interview responses. Finally, although the present study did not measure body image quality of life, Huang et al. found that participants with self-reported lipodystrophy demonstrated poor body image as measured by the Body Image Quality of Life Inventory (BIQLI). As the BIQLI was empirically validated on 110 college women (Cash & Fleming, 2002), it may not capture the distinct experience of being HIV positive or AIDS defined, experiencing lipodystrophic changes, and integrating these changes within an intersection of multiple marginalized identities. Future research may pilot and create measures to examine body image quality of life specific to the experiences of living as HIV or as AIDS defined.

Participants of the present study referenced fears about weight loss, though with distinct manifestations in comparison to the Tate and George (2001) study on body image in HIV positive gay men. In worrying about their body wasting or through the use of symbolic imagery, participants did express concern about a thin body appearance and related it to both a progressive disease state and even dying. However, participants expressed more concern about being unable to regulate extremes of body appearance, between too fat and too skinny, with a preference for appearing overweight than underweight. Unlike participants of the Tate and George study (2001), REHMHA did not check their reflections frequently in the mirror but rather avoided looking in the mirror as much as possible. REHMHA experienced loss of control over their bodies not only in how they experienced weight loss but also in how they experienced weight gain with efforts to hide and conceal with use of clothing and tattoos. Similar to the Tate and George (2001) study, REHMHA worried about interpretations of their body by family members, intimate partners, and their respective community.

Self-objectification has been defined as “adopting an observer’s perspective of the physical self” (Martins et al., 2007, p. 634) or “internalizing societal messages that view individuals’ value based on external factors leading to preoccupation with physical appearance” (Schwartz et al., 2010). In testing the applicability of objectification theory as a framework for examining sexual orientation differences in body experience, Martins et al. (2007) found that gay men experienced higher levels of self-objectification, body surveillance, body shame, drive for thinness, and upper and lower body dissatisfaction than heterosexual men. They reported that gay and heterosexual men experienced a similar drive for muscularity. Martins et al. (2007), however, did not account for HIV or AIDS defined status and racial/ethnic minority identification in examining objectification in heterosexual and gay males. Similar to the gay

men in Martins et al. (2007), REHMHA in this study also demonstrated self-objectification, engaged in body surveillance, experienced body shame, and reported both upper and lower body dissatisfaction.

The results of the present study suggest that objectification theory may be especially important in understanding REHMHA body image and body dissatisfaction. REHMHA's symbolic images of devaluation, marginalization, and death may reflect their internalization of a subjugated position (Chapman, 2000). Juhasz (1993) noted the tendency for dominant groups to depict and "look at the AIDS body as if they were women" (p. 151). REHMHA looked at their own bodies as less than men and less than women with symbols of skeletons, rodents, and insects representing bodies altered, and often times depicted as ravaged by HIV and/or HAART. These symbols may additionally point to a process of self-objectification and body dissatisfaction.

The racial ethnic minority body has often been placed on display, measured, and quantified to justify its subjugation or colonization (see Gould, 1996; Oates & Durham, 2004). In biomedical models of HIV care, the individual living with HIV or AIDS is often quantified with treatment success or failure indicated by medication adherence, viral load assay, and T-cell counts (Wong & Ussher, 2008). Biomedical models of HIV care are often characterized as creating a "disembodying" tendency (Wong & Ussher, 2008, p. 118). In the experience of HIV-related lipodystrophy, this may include overlooking how HAART could become visible and worn on the lipodystrophic body (Persson, 2004). The body living with HIV or AIDS has also been placed on negative display in social representations of deviant, out-group identities (Joffe, 1995). The participants of this study noted the potential for their bodies to be gazed upon in medical, social, and interpersonal encounters.

In comparing their bodies before HAART and then after HAART, participants demonstrated a shift in the way that they viewed their bodies. Before HAART, participants spoke of their bodies in valued socio-environmental, systemic, and cultural contexts including competition, the military, labor, exercise, sport, education, and relationships. Objectification theory was first used to describe the socialization of American women whereby cultural processes caused women to integrate the observer's perspective into their own self-conceptualization (Fredrickson & Roberts, 1997). Sexual objectification begets self-objectification. Objectified thinking means thinking of oneself as an object (Frederickson & Roberts, 1997). Associated with sex, deviant out-group identities, and contagion/bodily threat, the HIV/AIDS epidemic is very much a sexually objectifying circumstance that could lead to self-objectification for PLWHA (Zivi, 1998). Self-objectification could also become exacerbated by specific contexts (Fredrickson, Roberts, Noll, Quinn, & Twenge, 1998). In this study, self-objectification appeared to be further intensified by the participants' status as HIV or as AIDS defined, identities as racial/ethnic minority heterosexual males, and through the experiences of profound physical changes attributed to HAART.

The construction and enactment of alternative forms of masculinity may provide another useful lens to understand REHMHA's experience of body image. Charmaz (1994) noted that chronic illness "can reduce a man's status in masculine hierarchies, shift his power in relations with women, and raise self-doubts about masculinity" (p. 268). Further, behaviors may serve as a "currency" whereby men are able to assert their male gender and its representation of power, agency, and control in a patriarchal system that relies upon domination and subordination (Courtenay, 2011, p. 143). Thus, REHMHA's loss of control, from HIV or AIDS defined status and experience of lipodystrophy, and consequent behavioral efforts to regain control through

their bodies (e.g., rejecting intimacy, medication non-adherence, exercising against medical advice, appropriating use of clothing and tattoos) may be reflective of a reduction of their “status in masculine hierarchies” (Charmaz, 1994, p. 268)

Courtenay (2011) suggested that gender should be thought of as a verb rather than a noun; further, it requires constant relational interaction (Courtenay, 2011; West & Zimmerman, 1987), with the body as a necessary medium for the practice of gender (Connell, 1995). Thus, a man’s body serves as a vehicle through which he is able to construct, enact, and display his masculine identity (Connell, 1995; Courtenay, 2000). This examination of masculinities has been central to the examination of HIV-risk behavior (e.g., Bowleg et al., 2011); HIV disclosure (e.g., Dageid, Govender, & Gordon, 2012); stigma and social ostracism (Zivi, 1998); and HIV positive gay male body image and sexuality (Halkitis et al., 2007). In this study, the participants’ ability or inability to position themselves along dominant or subordinate trajectories of masculinity became paramount to understanding how they experienced lack of control or control over their body image (Davies & Harre, 1998). For some men, the physical effects of lipodystrophy became literal reminders of the kind of illegitimate identities and subordinated masculinities described by Connell (1995). The men often labeled themselves with pejorative descriptions such as “fat woman,” “fat boy,” “puny thing,” and “big titties.” These pejorative descriptions were also embodied in actions — refusal to look in the mirror, fear of emotional expression, denial of sexual intimacy, and a spectrum of risk behaviors (e.g., medication non-adherence, suicide attempt, exercising over medical advice, disengagement with care providers). Connell (1995) described the power of pejorative words in demarcating the boundaries between illegitimate and legitimate heterosexual masculinity, subordinate, and dominant masculinities.

At times, the men's behaviors, as expressed through both their words and bodies, seemed to habitually reaffirm their sense of illegitimate/subordinate heterosexual masculinity.

Courtenay (2011) noted that men occupying marginalized or subordinate roles in the masculine hierarchy may practice alternative forms of masculinity in attempt to prove that they are real men. These alternative forms of masculinity have been called by various terms including oppositional (Messerschmidt, 1993), compensatory (Pyke, 1996), and resistant (Courtenay, 2011) masculinity. They require the practice of hyper-masculine behaviors that may have dangerous or self-destructive consequences (e.g., use of violence, crime, fighting, rejecting medical care, high risk sexual behavior). The participants of this study were multiply marginalized by the intersections of their identities (e.g., living with HIV or as AIDS defined, racial/ethnic minorities, low SES) and automatically excluded them from qualification for the hegemonic standard characterized by the European American, high socio-economic status male (Courtenay, 2011). Even in marginalized masculine groups, REHMHA could not belong given their HIV status. Thus, the alternative forms of masculinity that they practiced appeared to be a manifestation of these identity intersections and the masculinity discourses in which they could or could not participate.

Most REHMHA in this study shifted between acknowledging their subordinate status while still aspiring to dominance and authority (Courtenay, 2011). A specific example of acknowledging their subordinate status with actions/behaviors was captured by how participants linked a diminished physical self-perception attributed to HAART with a decrease in sexual function. This decrease in sexual functioning as a result of body shape changes was similar to the findings of Turner's pre-HAART study on body image and sexuality in the context of AIDS wasting but dissimilar to Sharma's (2007) post HAART study, which noted no differences in

sexual dysfunction attributed to body shape changes. Other examples of shifting between subordination and seeking power/dominance included REHMHA's appropriation of tattooing (P.20) and clothing (P.16) to redirect their viewers' gaze; adhering to medication and select medical advice to 'pass' as non-HIV positive in their cultural communities (P.19); or engaging in competitive sport with other younger men in their communities thought not to be HIV positive and with the intention of feminizing other non-HIV positive men's behaviors (P.3).

In reaction to HIV or AIDS defined status and medication related physical changes, REHMHA often practiced alternative forms of masculinity with significant and dangerous health risks. Experiences ranged from a suicide attempt (P.17), to a jeopardizing exercise routine post-major surgery (P.4), to weight monitoring leading to medication breaks from HAART (P.21 and P.12). Whether medication non-adherence or weight monitoring, REHMHA's health-related behaviors demonstrated attempts to regain power, control, and construct gender (Courtenay, 2011). If gender enactments rely upon one's position in social structures (Messerschmidt, 1993), then having any degree of power within these social structures required REHMHA to be able to conceal their HIV positive or AIDS defined status (Persson & Richards, 2008). REHMHA often engaged in dangerous health risks precisely because they believed they would maintain the secret of their disease status.

Self-objectification and engagement with alternative masculinity practices may lead to psychological consequences and mental health risks (e.g., depression, sexual dysfunction) (Courtenay, 2011; Fredrickson et al., 1998). The experience of lipodystrophy and process of self-objectification may be further compounded by mental health problems already associated with or exacerbated by HIV. Cournos and McKinnon (2008) noted: "HIV is a neurotropic virus that enters the central nervous system at the time of initial infection and persists there" (p. 40). The

majority of PLWHA will experience a diagnosable psychiatric illness (Stoff, Mitnick, & Kalichman, 2004) and are twice as likely than those without HIV to be diagnosed with a major depression (Ciesla & Roberts, 2001). These high prevalence rates exist irrespective of geographical or cultural difference in PLWHA (Rabkin, 2008). The participants of the present study reported a spectrum of distress related to biological (e.g., pain, loss of mobility, fat accumulation/fat loss, skin, hair and nail changes, fatigue); psychological (e.g., depression, anxiety, suicidality); social (e.g., alienation, isolation, stigma, loss of independence, unemployment, loss of former meaning, loss of intimacy) experiences.

One of the most prominent areas of psychological distress for REHMA was related to intimacy and warrants further exploration. The majority of participants ($n = 19$) described a trajectory of limiting acts of intimacy from intentionally not engaging in sex to refusing to be touched. It would be erroneous to assume that the participants' limitations of acts of intimacy were only related to their infectious disease status with fear of transmitting the virus, being unaware of safer sexual practice, or not having appropriate contact with prevention services. A prioritization of prevention models and focus on unsafe sexual practice has limited what is known about the sexual experiences of PLWHA (Siegel, Schrimshaw, & Lekas, 2006). In fact, most participants spoke of limiting acts of intimacy because of HAART-related physical changes that increased bodily dissatisfaction, psychological distress, and physical pain. When participants did speak of themselves as "contagious," they tended to reference internalized stigma and self-objectification rather than lack of awareness of safer sexual practices.

P.5, for example, demonstrated high levels of health literacy on HIV and safer sexual practice throughout his interview. Nonetheless, he felt triggered by the observation of HAART-related hyperpigmentation and skin discoloration with intense emotions (e.g., "pride,

embarrassment, shame, and fear”) and an internalization of self as a contagious other (e.g., fear of “getting somebody else sick besides me”). P.5’s decision to be sexually abstinent with his partner may be representative of the interaction between external (e.g., social/cultural influence) and internal (e.g., psychological, biological, and medical) processes. REHMHA have been depicted as embodying a “monstrous masculinity” (Persson & Newman, 2008, p. 632), sexually insatiable, and portrayed in news media as intentionally infecting innocent females with HIV, suggesting another out-group, deviant, and criminal identity. Like P.5, other REHMHA in the current study appeared to be aware of these discourses. REHMHA’s actions could be interpreted as a manifestation of self-objectification, adopting an observer’s or social perception of their bodies as contagious threat. Understanding safer sexual practice would not necessarily erase the external and internal stigma. REHMHA’s actions could also be thought of as enacting an alternative form of masculinity that valued protection, honor, and/or authority (Abreu, Goodyear, Campos, & Newcomb, 2000; Mosquera, 2011) —aspects of masculinity that are essentially socially negated through becoming HIV positive.

Other participants reported physical transformations from lipodystrophy or the pain associated with these changes as affecting acts of intimacy. P.7 reported feeling sexually unattractive because of abdominal fat accumulation and attempts to “try to get out of” sexual intimacy. P.10 felt disgusted by the appearance of his thin arms, haunted by the thought of what they might look like holding his female partner whose arms were noticeably bigger than his own. P.2 discussed the relationship between limiting acts of intimacy and the physical pain experienced from gluteal fat wasting. Still others like P.13 rejected being touched altogether, marking their sense of complete difference and separation from others: “no one can understand me.”

These findings suggest a need for interventions that tackle the negative effects of self-objectification and unhealthy gender enactments to increase sexual health, psychological health, and social support. For example, REHMHA should be evaluated for HIV or HAART-related sexual dysfunction. Scanavino (2011) noted the prevalence of sexual dysfunction with the advent of HAART including high rates of erectile dysfunction (up to 74%), ejaculatory disturbance (up to 42%), and low sexual desire (up to 73%) with the pathophysiology of sexual dysfunction from HAART being poorly understood. It is known, however, that all antiretroviral therapies are associated with sexual dysfunction (Scanavino, 2011). Pharmacotherapy has been used for male sexual dysfunction and includes PDE-5 inhibitors for erectile dysfunction, testosterone replacement, and letrozole for improvement in sexual desire (Scanavino, 2011).

Physicians can approach the topic of sexual health both directly and through exploring how REHMHA body image affects sexual health. Participants' responses highlight the importance of creating an open and honest dialogue that includes and seeks to go beyond prevention and safer sex measures to ask REHMHA about the quality of their sex lives. As one participant stated: "we know about safer sex probably more than anybody else. And they [hospital staff] are sure that we know how to protect ourselves but my doctor doesn't ask how my sex life is." The World Health Organization (2010) defines sexual health as:

...a state of physical, emotional, mental and social well-being in relation to sexuality; it is not merely the absence of disease, dysfunction or infirmity. Sexual health requires a positive and respectful approach to sexuality and sexual relationships, as well as the possibility of having pleasurable and safe sexual experiences... (p. 3)

Both psychologists and other members of integrated HIV care teams (IHC) may be able to further assess and create interventions around sexual health. Scanavino (2011) suggested that supportive and psychosexual therapy might be useful in treating

psychogenic causes of sexual dysfunction. The IHC does not, however, have to wait for a patient to report sexual dysfunction but should rather incorporate sexual health and body image as a standard of care. Such a practice would involve creating clinical cultures where conversations about sexual health and body image are routine rather than extraordinary. For example, if IHC members only ask about sexual health in terms of prevention or safer sex practices, REHMHA may be suspicious or even unwilling to speak about other aspects of sexual health (e.g., understanding how the body works in relation to sexual response and pleasure, sexual health concerns related to emotional attachment including sexual decision-making and skill building, and need for health promoting behaviors for early identification of sexual problems including regular check-ups and testicular self-scans; WHO, 2010). As counseling psychologists strive to achieve multicultural competencies and work within a social justice framework (Vera & Speight, 2003), they may be especially equipped to both create prevention and intervention strategies for REHMHA and train IHC teams in increasing multicultural and social justice competencies in their interactions with REHMHA on sexual health and body image.

REHMHA's responses on the topic of sexual health and intimacy echoed a pervasive sense of loneliness, isolation, and even depression felt by participants. In the super-ordinate theme of "navigating social dimensions of visibility and invisibility", most REHMHA could not relate to the representation of Magic Johnson in the media and often noted the complete absence of REHMHA in media. In conversations with disparaging or negative comments about PLWHA, participants often positioned themselves as almost invisible spectators, listeners, and observers.

In a qualitative study of heterosexuality and HIV in Australia, Persson and Richards (2008) found that participants separated HIV from other aspects of their lives, preferring passing or not speaking about HIV/making every effort to conceal their HIV status. As one participant of their study revealed: “HIV, if you are straight, is an unshareable thing. If you’re gay it’s shareable but if you’re straight, it’s not because it makes you so foreign” (Persson & Richards, 2008, p. 76). Similar to the men of the Persson and Richards (2008) study, REHMHA also felt that HIV was an “unshareable thing,” had little or no contact with other heterosexual men living with HIV or as AIDS defined, and had no other community to build an alternative existence. In contrast, being from Australia and identifying as White, the men of the Persson and Richards (2008) study did not have the experience of racial/ethnic minority status in the United States or racial/ethnic minority immigrant status. The inability to share, to stay invisible was also apparent in how the men of the present study went through extensive efforts to conceal or distract observers of their body through the targeted use of clothing and even tattoos or distanced themselves from experiencing intimacy.

Increasing actual social support (e.g., number of friends) may be one solution to decrease loneliness and isolation and increase positive mental health outcomes for REHMHA. Most studies examining social support in HIV or AIDS defined populations have largely focused on the experiences of gay HIV positive or AIDS defined males with little or no heterosexual or straight males included in the sample populations (e.g., Burgoyne & Saunders, 2000 Kadushin, 1999). In a sample of gay, bisexual, straight men ($n = 232$), and women ($n = 125$; no sexual orientation specified), McDowell and Serovich (2007) found that straight men experienced perceived support (i.e., the perception of

support received from others) rather than actual support (i.e., actual availability of social support) as predictive of mental health.

The construct of perceived support may assist in understanding participant responses related to gay HIV positive or AIDS defined men. While REHMHA's positive attitudes towards gay HIV positive or AIDS defined men may be conceptualized as a form of homophobia, an attempt to separate their bodies and experiences from gay men, their attitudes may also relate to their perception of gay men as having more support and being more supported. The participants admired the ability of gay identified HIV positive or AIDS defined men to combat negative social representations and build an alternative form of community. The men spoke of a marked differentiation between the solidarity of the HIV positive gay community versus the disenfranchisement of the HIV positive heterosexual community. Their perceptions about the solidarity of the gay community were informed by media images, the significant representation of gay men observed in HIV-related magazines in their medical clinic, and limited interactions with HIV positive gay men in their community or within the medical care setting. In an Australian sample, Bartos and McDonald (2000) reported that nearly one-quarter of HIV positive heterosexual men never read HIV-related press in comparison to less than 5% HIV positive heterosexual or lesbian women and gay/bisexual men (Bartos & McDonald, 2000). Although similar statistics are not available for PLWHA in the United States, it is reasonable to assume that the failure to see representative images or topics in HIV-related press may perpetuate a further perception of a divide between groups that are visible and thought of as cohesive (e.g., gay HIV positive men) and groups that are invisible and existing on the periphery (e.g., REHMHA).

McDonald and Serovich (2007) suggested perceived social support is predictive of mental health for heterosexual or straight men living with HIV or as AIDS defined. Even REHMHA with small social networks could potentially feel adequately supported. IHC teams could assess the degree to which REHMHA feel that they have the resources they need. It is also suggested that psychologists could help REHMHA identify dimensions of support. This information may be especially important to how REHMHA perceive support related to their experience of body image. Integrating body image into routine clinical care may increase REHMHA's sense of support. For example, a psychologist may meet with REHMHA after a medical visit to speak with them specifically about body image and the identified individual(s) he believes he could speak to about body image if needing support. A dietician may integrate body image into nutritional assessments and intakes. A case manager may inquire if REHMHA have sufficient financial resources to support nutritional goals. An adherence nurse may integrate body image through asking REHMHA questions about adherence in relation to perceived lipodystrophic changes. A physician could create a dialogue about lipodystrophy by having the client fill out the PLS and then talking about the results during the clinic appointment. In this study, REHMHA felt particularly concerned about being seen in the group setting with past attempts at establishing psychotherapy and support groups for heterosexual males living with HIV or as AIDS defined as having no participation, even with monetary incentives. For this study, 10 REHMHA participated in open research team meetings though individually and making sure that no unknown individuals were present. REHMHA came to team meetings upon the follow-up of one research team member who identified as heterosexual, a long-term AIDS survivor, and worked intimately with this particular clinical community.

This research team member's presence may suggest other smaller scale interventions that could increase support for REHMHA. Peer support programs have been endorsed by the Substance Abuse and Mental Health Services Administration (SAMHSA) and have been used as a mechanism for individuals who recovered from mental health and/or substance abuse to help other peers who are undergoing recovery (SAMHSA, 2009). They are considered a consumer operated evidence based practice and may include multiple peer support practices such as one to one peer mentoring, peer support groups, help in accessing health and community services, transportation, and wellness coaching. Moreover, these services are reimbursable through Medicaid (Pennsylvania Recovery and Resiliency, 2014). Given the high rates of diagnosable mental health and substance use disorders experienced amongst PLWHA, peer support services provide an additional mechanism for support in the HIV clinical care setting. Further, they could be adapted to offer REHMHA as well as other PLWHA an array of options from one to one peer mentoring to wellness coaching to address body image and behavioral health.

Corrective procedures and/or surgery for lipodystrophy may be considered for REHMHA experiencing physical and psychological distress. Nineteen percent of the current study's sample underwent corrective surgery for lipodystrophy. Procedures included liposuction for HAART-induced enlargement of the breast tissue or gynecomastia, cheek implants or facial fillers for facial wasting, liposuction for buffalo hump, and a panniculectomy to remove excess abdominal and skin fat. Although more PLWHA have been requesting surgical procedures to correct lipodystrophy (Davison, Timpone, & Hannan, 2007), the majority of participants in this study either did not know that corrective surgical procedures existed, knew that their insurance would only pay for a fraction of the potential procedures, were eligible for patient assistance programs but could not afford procedural costs not covered by insurance, were not eligible for patient

assistance programs because of undocumented immigrant status (see Sculptra Patient Access Program, 2015), or could not afford long-term costs associated with temporary corrective procedures (e.g., maintenance of facial filler injections or recombinant human growth hormones to target excess abdominal fat).

As PLWHA must continue to take HAART for survival, lipodystrophy could return after corrective surgical interventions and may require specific HIV related competencies for plastic surgeons and medical teams assisting in post-surgical recovery to reduce the risk of complications (Tanna, Venturi, & Olding, 2005; Vella, 2015). Whether corrective or surgical procedures are temporary or permanent, it could be argued that REHMHA experiencing lipodystrophy should be afforded a choice similar to women who elect to and are insured to have breast reconstruction after mastectomies. Psychologists treating REHMHA may serve as essential advocates relating the deleterious effects of lipodystrophy on the quality of life and mental health of PLWHA.

Other areas of intervention that may contribute to the physical and psychological health of REHMHA include an examination of patient/provider dialogue in IHC teams; the incorporation of identity in REHMHA body image and care; and increasing cultural competencies of REHMHA providers. REHMHA identified open and honest conversations with their doctors as having repercussions in other facets of their care, including limitation or enhancement of social service benefits. Used in geographically and time constrained clinic environments, IHC aims to enhance HAART adherence, reduce HIV viral load, and enhance care outcomes through providing patients access to wraparound resources (e.g., care for hepatitis C co-infection, behavioral health, and substance abuse services, nutritional services; Hoang et al., 2009). Providers, however, should also be aware of how IHC may deter open and honest

conversations as REHMHA navigate multiple dimensions of power. In the present study, some participants feared doctors would report medication non-adherence to case managers with loss of social and medical benefits. Whether real or perceived, patient concerns about dimensions of power within IHC may assist providers in thinking about issues of confidentiality, how they choose to share information with other team members, and how they frame conversations with REHMHA to build a stronger working alliance. For example, the provider may create a more equitable conversation by acknowledging patients' potential fears, explicitly addressing how patient information is disseminated in IHC teams, and explaining the purpose or rationale for information that must be shared for continuity of care.

The responses of participants of this study also emphasize the essential role of considering identity and body image in REHMHA care. The collection of patient demographic information may provide the very first opportunity for a patient to express or ascertain the limitations placed on their identification. Providing participants the opportunity to define their own perception of skin color, name their ethnic understanding, and primary and secondary languages spoken revealed the complex diversities of this patient population with potential implications for conducting future research on REHMHA body image and creating meaningful interventions.

Examining REHMHA's experiences of body image may also assist in creating interdisciplinary interventions and enhancing provider cultural competencies. As a starting point, body image must be acknowledged as an important facet of REHMHA care. Neglecting to initiate a conversation on body image may represent a missed opportunity for the provider to improve understanding of how body image interacts with mental health, sexual health, and engagement in risk behaviors (e.g., non-adherence, self-harm). With high clinical caseloads,

HIV providers may state that they simply do not have time to initiate these conversations.

Working within multidisciplinary care teams and creating a clinical culture where body image is considered and addressed, however, holds the potential to inspire prevention and intervention strategies that may ultimately increase REHMHA positive engagement in care and lessen adverse health outcomes.

The men's experience of body image provides insight for future research and piloting of prevention and intervention strategies. These future efforts might take the form of both evaluative questions and assessments. Evaluative questions may include inquiring about attitude towards HAART and its interaction with body image; how REHMHA thinks of the ideal body and the expectations he has for his own body; using a scale such as the PLS as an initial point of conversation on body image, understanding what gives REHMHA's body meaning; considering other facets of body image beyond muscularity and adiposity as being relevant to body satisfaction or dissatisfaction; observing how REHMHA enhance or mask their bodies through clothing and tattooing; speaking to REHMHA about the satisfaction or dissatisfaction of their sexual lives; assessing for the role of body image in self-harm or risk behaviors. Assessments may take into account the role of symbol, metaphor, and language to more holistically assess perceptual body image disturbance into shape/size considerations; incorporating an understanding of masculinity (ies) into expressions of body image behavior; and considering how men understand subjective body image through larger social experience of navigating visibility and invisibility.

The participants' insights also point out the need for HIV clinical cultures that are open and that strive for increasing their cultural competencies. It may require providers to engage in a self-reflective process, understanding how their own identities have the potential to impact their

patients' engagement in care. The majority of men in the present study perceived HAART as having a profoundly negative impact on their body image. Schilder et al. (2001) noted the importance of clinician awareness of the "psychological and social contexts within which antiretroviral therapies are used" (p. 1643). Having this kind of awareness would require the provider to be more attuned to the difference between provider values and patient valuing (Stone, 2004). For example, the men did not feel their doctors understood their dilemma of balancing weight loss and weight gain, reported a difference between their doctor's understanding of ideal weight and their own sense of ideal weight, feared the translatability of their bodies in their community, and often engaged in risks such as medication non-adherence or exercising against medical advice because of these bodily preoccupations.

Several participants' reported holding different perspectives in comparison to their providers on HAART adherence. Research indicates how complex the consequences of non-adherence could be with the potential for viral mutations with wrong dose timing (i.e., not taking HAART at or about the same time daily), short breaks from HAART (e.g., 2 days), extended breaks from HAART, and even consecutive or non-consecutive short or long breaks to be important to short and long-term treatment success (Bangsberg, 2006). While there is variation depending upon the antiretroviral drug class, most studies report that HAART adherence should exceed 95% to be truly effective (Lima et al., 2010). Participants in this study seemed to acknowledge a risk (e.g., in medication of resistance, in knowing they would need to re-engage medication adherence) but still admitted to periods of non-adherence with the aim of controlling for physical transformations attributed to HAART at least temporarily. Moreover, some men felt as if they could not talk about effects of HIV medications in their lives or on their bodies citing denial (e.g., "I've had my doctors deny what these medications do. That's ok. I know cuz' I live

with me”), not wanting to disappoint their doctors (e.g., “I could never, ever tell my doctor that I wasn’t taking these meds all the time. He would tell me no, that I couldn’t do that. He’s like my pops”), or statements implying a power imbalance (e.g., “Doc is about the numbers [referencing his HIV viral load], they should be what he wants them to be”). In a study on HIV positive patient involvement in health decisions and outcomes ($N = 1,027$), Beach, Duggan, and Moore (2007) found that patients who prefer that their HIV provider make all or most decisions were less likely to adhere to HAART. Although the participants of this study did not prefer that their providers make all or most decisions, they also did not express preferences, decisions, or ideas in their medical encounters.

African Native participants demonstrated a different perspective on HAART non-adherence than non African Native participants. Whereas African Native participants connected HAART non-adherence to almost instantaneously taking on the appearance of AIDS wasting syndrome, non African Native participants felt as if they could more effectively balance weight loss and weight gain by controlling their adherence (as described above). Providers should be aware about how cultural representations of the HIV or AIDS body may inform their patients’ adherence decisions and body image conceptualizations. Although the African Native participants spoke about faithfully adhering to HAART, they did not equate adherence to greater body image satisfaction. Most African Native participants believed that HAART adherence would assist them in keeping the secret of their disease serostatus, maintaining socio-economic viability despite undocumented immigrant status, and protection in their respective cultural community. These participants, however, did not discuss engaging in patient-centered conversations with their providers. While African Native participants regarded their doctors’ advice for HAART adherence, they selectively listened to their doctors’ advice in caring for

other disease processes. They reported non-adherence to medications for diabetes and cardiovascular disease and did not go for imaging tests despite hospital patient assistance that would pay for all costs related to imaging studies.

Kremer, Bader, O Cleirigh, Bierhoff, and Brockmeyer (2004) noted the prevalence of a paternalistic medical model in physician providers approach to HAART adherence characterized by an unquestioning patient and treatment failure as the patient's failure. The decision to take medications or follow medical advice is highly complex, especially given what is still unknown both about HIV and HAART. Speaking to REHMHA about body image, including body image satisfaction and dissatisfaction, may assist providers in gaining more information about their patients' values, desire, and/or ability to engage with medical care.

Cargill (2013) proposed a socio-ecological framework for correcting HIV disparities amongst marginalized and vulnerable populations with HIV as a single factor amongst multiple socio-ecological disparities including unemployment, poverty, education, geographic location, health literacy, stigma, violence, and limited or no insurance. The socio-ecological approach is "particularly useful in addressing health behaviors that are influenced by factors such as culture, trust, and beliefs with prenatal and weight loss interventions being prime examples (p. 134)." Thinking about body image in a socio-ecological framework may be useful to HIV providers in engaging REHMHA in a more patient centered model of care. In this study, REHMHA's culture, trust, and beliefs impacted how they thought about their bodies, how they navigated medical decision making, and how they created relationships with their medical providers. In asking REHMHA about bodies in a collaborative instead of a paternalistic way, providers could find out invaluable information regarding health literacy (e.g., REHMHA knowledge about HAART, adherence behaviors, HIV, engaging in other medical care related or non-related to

HIV); poverty and unemployment (e.g., how socio-economic factors relate to nutrition, ability to exercise, understanding of and access to corrective interventions for lipodystrophy); stigma (e.g., internal, social, cultural, and structural manifestations of stigma); and geographic location (e.g., how being a REHMHA in a specific geographic location influences physical interactions, what one expects from their body).

Limitations, Strengths, and Conclusion

IPA emphasizes idiography or a focus on the particular— particular participants in a particular context (Smith et al., 2013). It also emphasizes the relational world of the individual in his/her environmental context with the potential to reflect and move towards the shared universal (Smith et al., 2013). Using interpretative phenomenological analysis, this study explores the body image experience of 21 REHMHA from a specific geographical region, in a specific clinical context, and with specific self-identified demographic characteristics. Using a purposeful sampling strategy, this study did reflect the racial/ethnic demographic identity characteristics of the hospital based research site. As no participants identified as Asian or Asian American and living with HIV or as AIDS defined at this research site, these voices and experiences could not be included. In addition, the research team was only able to recruit two males under the age of 30 to this study, one of who contracted HIV through perinatal transmission and could be categorized as a long-term HIV or AIDS survivor. Approximately 50% of children infected with HIV through perinatal transmission exhibit poor growth. Vitamin deficiencies, neuroendocrine abnormalities, infections of the gastrointestinal track, and malabsorption are also common (Arpadi, 2000). Dietary supplements were found to improve weight but not lean tissue and height (Arpadi, 2000). Thus, it is not known how potentially

experiencing poor growth may have affected the body image experience of this young adult REHMHA participant.

Body image may be experienced differently for younger REHMHA cohorts who are not long-term survivors and of alternative HIV transmission categories (e.g., heterosexual sex, injection drug use). As noted, 15 potential participants who did not respond to the research invitation were in their early 20s and early 30s. These potential participants were also not as engaged in their health care at the hospital clinic in comparison to the REHMHA who did participate in this study. Courtenay (2011) noted that men and boys are less likely to engage in health promoting behaviors, more likely to engage in risk taking behaviors, and respond to stress with avoidant coping strategies.

In an early study on coping with AIDS, Fleishman and Fogel (1994) found that respondents with a history of injection drug use had more avoidant coping styles than gay or bisexual men, and higher levels of depressive symptoms were also found amongst minorities, those of low socioeconomic status, drug users, and women. These respondents were more likely to deny negative feelings or distract themselves from such feelings (Fleishman & Fogel, 1994). Although the Fleishman and Fogel (1994) study did not specifically examine age as a factor, it is possible that younger REHMHA may use avoidant coping strategies to deal with HIV or AIDS defined status especially given the multiple stigmas that could be experienced for young REHMHA (e.g., young adults, heterosexual, racial/ethnic minorities, HIV positive or AIDS defined, discrimination, residential segregation, disproportionate rates of incarceration and police brutality, internalized stigma, and other structural stigmas increasing health disparities).

Older REHMHA or REHMHA with perinatal infection transmission may experience similar stigmas, engage in avoidant coping strategies, and experience depressive symptoms.

These participant cohorts, however, answered the research invitation and participated in the study with a high degree of enthusiasm. Several research participants of these cohorts intensely approached the semi-structured interview with the following statements: “I need to talk about this;” “I don’t understand why we are not included in more research studies;” “this is so important to be asked about this.” Moreover, these cohorts also survived the uncertainty of survival in the pre-HAART era and then the uncertainty of physical revival and medication side effects of the post-HAART era (Brashers et al., 1991; Cochrane, 2003). The cohorts’ approach to the research invitation may speak to their experiences of disenfranchisement including perinatal infection, long-term AIDS defined survivorhood, and as heterosexual men identifying as racial/ethnic minorities and diagnosed as AIDS defined when this epidemic was thought to predominately affect gay men (CDC, 1982). Their body image experiences may also reflect the imprint of prolonged exposure to HIV medications (Persson, 2004), an experience that is not shared with more newly diagnosed REHMA.

IPA as an analytic technique captures a double hermeneutic of participant and researcher as they try to make sense out of lived experience (Smith et al., 2013). This study was based upon the participants’ self-report as well as self-attribution or their perception of body related changes thought to be the result of HAART. Participants may have not accounted for other confounding factors in their construction of body image including how disease co-morbidity, diet, exercise, and physical and metabolic age related changes affect body shape and size dimensions.

Most qualitative studies on topics related to HIV and racial/ethnic minority heterosexual men have explored assessment of potential HIV behavioral risk (e.g., multiple sexual encounters, attitudes about condom use) in samples of racial and ethnic minority heterosexual men who are not known to be HIV positive (e.g., Bowleg, 2011a; Bowleg et al., 2011). Although these

studies are undoubtedly important, they do not help providers move towards understanding the qualitative experiences of racial and ethnic minority heterosexual men who are already known to be HIV positive or AIDS defined. The few qualitative studies that do exist with HIV positive heterosexual male participants do not focus exclusively on racial or ethnic minority status as a unique identity variable and mix HIV positive heterosexual male experience with the experience of HIV positive females. Topics examined within these qualitative studies include HAART adherence (e.g., Remien et al., 2003), serodiscordant relationships or being in a relationship with a non-HIV positive partner (e.g., Van Der Straten, Vernon, Gomez, & Padian, 1998), and HIV status disclosure (e.g., Cusick & Rhodes, 1999; Persson & Richards, 2008).

To the author's knowledge, this study is the first to exclusively explore the body image experiences of REHMHA. Yancey, Ortega, and Kumanyika (2006) noted the urgent need to increase individuals identifying as racial and ethnic minorities in qualitative and quantitative research to decrease racial/ethnic disparities in health outcomes and healthcare. Factors noted by this study's participants — invisibility, disenfranchisement, and stigma — may render the recruitment of REHMHA especially difficult, requiring a pre-existing investment in the HIV community, a clinical presence, and representative members of HIV care teams. One of this study's strengths is an in-depth focus on the lived experience of REHMHA, a population that has been historically difficult to recruit (Silvestre et al., 2006). REHMHA were not only recruited but also actively engaged in other stages of the research process including attending research team meetings, check-ins, and participated in member checks for respondent feedback. As previously noted, part of our research team engagement strategy was the use of a research team member with extensive work in this particular clinic community, identified as heterosexual, and a long-term AIDS defined survivor. This research team member may have influenced

REHMHA participation in open research team meetings. He followed up with participants via the phone or in person at the clinic to remind participants of the possibility of attending these meetings. During these open team meetings, the research team member sat in a central and visible location. The research team members felt that REHMHA participation in team meetings better ensured the accuracy of the lived experience and interpretations presented. In addition to a research team member known within this specific community, our research team included a highly diverse and interdisciplinary team of individuals with up to 20 years of experiencing working with REHMHA and a deep understanding of this population. Research team members participated in recruitment, transcription of interviews, analysis of surveys/questionnaires and semi-structured interviews including data coding and checking in with participants concerning collected data or gathering additional information.

The results of this study suggest the importance of REHMHA recruitment and participation with 21 REHMHA participants demonstrating high levels of body image dissatisfaction. Participants spoke about their body image experiences through describing the valued male body and contrasting this body with their own sense of a devalued body. They expressed these concerns with shape/size dimensions, language, symbol, and emphasizing the socio-environmental, systemic, or culturally contexts that appeared to give their bodies both value and meaning. Through narratives of losing and gaining control participants reacted to their HIV/AIDS defined status and lipodystrophic changes by enacting and renegotiating dimensions of power. The ability to lose control and gain control was experienced in routine, intimacy, clothing and tattooing, exercise routines, and engagement or disengagement with medical care.

Finally, participants understood their body image through navigating social dimensions of visibility and invisibility. Often navigating this precarious terrain required participants to gain

new ways of seeing their bodies in a broader socio-cultural context including media representation, the workforce, in actively or passively engaging conversations about REHMHA, and in contrasting their individual and collective invisibility and disenfranchisement to perceived visibility and advocacy of HIV positive or AIDS defined gay men in their lives and communities.

Qualitative studies examining lipodystrophy focus on the experiences HIV positive men identified as gay, men who have sex with men (MSM), or homosexual and HIV positive women (e.g., Collins et al., 2000; Gagnon & Holmes, 2011; Tate & George, 2001, Varas-Diaz et al., 2005). The qualitative body image experiences of REHMHA should be explored and understood for several reasons. First, HAART induced lipodystrophy has been associated with multiple negative consequences including depression and anxiety (Crane et al., 2008; Collins et al., 2000), poor quality of life (Blanch et al., 2002), disruption of patient provider alliance (Gagnon & Holmes, 2011), stigma (Varas-Diaz et al., 2005), and HAART non-adherence (Sansone et al., 2004) with the potential to increase health complications and decrease life expectancy (Stone et al., 2004). Second, individuals classified as racial and ethnic minorities carry the burden of all health disparities in the United States including HIV (KFF, 2013; USHHS, 2009), and heterosexuals living with HIV or as AIDS defined make up 70% of HIV infections globally (Dworkin et al., 2009). Thus, qualitative research on body image, HAART, and lipodystrophy should expand to include the voices of a population that it may affect the most. Finally, a qualitative framework may ease the “disembodying” tendency (Wong & Ussher, 2008, p. 118) of biomedical models of HIV care with REHMHA’s body image experience allowing for nuanced approaches to assessment and interventions that create patient-centered care.

Executive Summary

Introduction. People living with HIV or as AIDS defined (PLWHA) may experience significant physical and metabolic alterations (i.e., lipodystrophy syndrome) as a side effect of HIV medications (i.e., highly active antiretroviral therapy or HAART) leading to profound transformations in body image (Collins et al., 2000; Reynolds et al., 2006). Lipodystrophy syndrome embodies patterns of bodily fat redistribution that include body fat gain (i.e., lipohyperatrophy), body fat loss (i.e., lipoatrophy), or a mixture of body fat gain and loss (Bonnet, 2010). Despite the significant percentage of racial/ethnic minority heterosexual men living with HIV or as AIDS defined (REHMHA) both in the United States and globally and the known adverse effects of HAART on the body, the body image experiences of REHMHA have been unaccounted for in quantitative or qualitative research. The purpose of this study was to qualitatively explore the body image experiences of HIV positive males who self-identified as heterosexual, racial/ethnic minorities, and were taking or had a history of taking HAART.

Method. Using interpretative phenomenological analysis (IPA), body image was explored across perceptual, behavioral, and subjective dimensions (Thompson, 1990). Twenty-one participants (ages 23-67 years; mean age = 48 years; mean years living with disease = 15.7 years) were purposefully chosen for this study based upon specific inclusion criteria including being patients at the hospital based infectious disease clinic (the site of this research study), a diagnosis of being HIV positive or AIDS defined, identification as racial/ethnic minority, and taking HAART for a minimum of six months currently or in the past. Instruments included a semi-structured interview on body image, a demographic questionnaire, a body image questionnaire, and a Perception of Lipodystrophy Scale (PLS). Trustworthiness was established through a total of 7 interdisciplinary research team members with up to 20 years working with

REHMHA; self-reflexive memos, bracketing; transcription checks; use of participant check-ins and participation in research team meetings; use of consensus; interview and other data sources as a form of triangulation; reoccurrence across for super-ordinate and emergent themes.

Results. Three super-ordinate themes were found for the body image experiences of REHMHA. In the first super-ordinate theme, “describing the valued and devalued body,” participants consistently made reference to the valued body for other men and the devalued body for REHMHA. REHMHA contrasted the valued/devalued through shape and size dimensions, use of symbol, and comparison of self before HIV or AIDS defined status and after HIV or AIDS defined status and taking HAART. The second super-ordinate theme “losing and gaining control” refers to how REHMHA experienced loss of control and sought to gain control over their feelings, perceptions, and behaviors with respect to HIV or AIDS defined status and/or physical transformations experienced post-HAART in routine activities, intimacy, use of clothing and tattoos, and engagement with medical care, and the medical community. The third super-ordinate theme “navigating social dimensions of visibility and invisibility” describes how men understand their body image through a deeper social cultural lens including representation in the media, interpretations of their bodies specifically in relation to their ability to work/labor, and finally through comparing their invisibility to the visibility of HIV positive or AIDS defined gay men.

Discussion. Two frameworks may assist in understanding the body image experiences of REHMHA—objectification theory and masculinity. Self-objectification occurs when an individual adopts “an observer’s perspective on the physical self” (Martins et al., 2007, p. 634). Self-objectification can create significant psychological distress and consequent mental health risks. The results of this study suggest that REHMHA undergo a process of self-objectification

from the diagnosis of HIV or AIDS defined status and HAART-induced physical transformations. REHMHA appear to react to body image dissatisfaction and disturbance through constructing alternative forms of masculinity as they are multiple marginalized because of their racial/ethnic minority status and HIV or AIDS defined status. Although REHMHA's alternative forms of masculinity sought to regain power, agency, and control, they nonetheless may negatively influence physical and mental health.

Through the exploration of body image, psychologists and other members of integrated HIV care teams (IHC) may uncover a wealth of information related to mental health, sexual health, social behavior, adherence, and other physical health behaviors. With this information, meaningful interventions may be developed with the intent of increasing REHMHA health promoting behaviors and decreasing isolation and adverse physical and mental health risks. Suggestions for intervention include: the piloting and creation of body image assessments specific to REHMHA, incorporating body image into routine clinical care, evaluating sexual health through body image, establishing peer support services to provide REHMHA with tailored support options that meet their individual preferences from one to one peer support to wellness coaching, and advocating for the inclusion of insurance covered corrective or surgical procedures for lipodystrophy. Finally, the results highlight the importance of HIV providers who strive to increase their cultural competencies and the need for researchers to create qualitative and quantitative studies that are more inclusive of the specific experiences and needs of REHMHA.

References

- Abreu, J. M., Goodyear, R. K., Campos, A., & Newcomb, M. D. (2000). Ethnic belonging and traditional masculinity ideology among African Americans, European Americans, and Latinos. *Psychology of Men & Masculinity, 1*(2), 75-86. doi: 10.1037//1524-9220.1.2.75
- Adimora, A.A., & Schoenbach, V.J. (2002). Contextual factors in the black-white disparity in heterosexual HIV transmission. *Epidemiology and Society, 13*(6), 707-712. Retrieved from <http://www.jstor.org/stable/3703485>
- Adimora, A.A., & Schoenbach, V.J. (2005). Social context, sexual networks, and racial disparities in rates of sexual transmitted infections. *The Journal of Infectious Disease, 191*(1), S115-S122. doi: 10.1086/425280
- Akan, G.E., & Grilo, C.M. (1995). Sociocultural influences on eating attitudes and behaviors, body image, and psychological functioning: A comparison of African-American, Asian-American, and Caucasian college women. *International Journal of Eating Disorders, 18*, 181-187.
- Ammassari, A., Antinori, A., Cozzi-Lepri, A., Trottam, M.P., Nasti, G.,...Galli, M. (2002) Relationship between HAART adherence and adipose tissue alterations. *Journal of Acquired Immune Deficiency Syndromes, 31*(3), 140-144.
- Andany, N., Raboud, J.M., Walmsley, S., Diong, C., Rourke, S., Rueda, S.,...Loufty, M.R. (2011). Ethnicity and gender differences in lipodystrophy of HIV-positive individuals taking antiretroviral therapy in Ontario, Canada. *HIV Clinical Trials, 12*(2), 89-103. doi: 10.1310/hct1202-89
- Arpadi, S. M. (2000). Growth failure in children with HIV infection. *Journal of Acquired Immune Deficiency Syndromes, 25*(1), S37-S42.

- Babl, J.D. (1979). Compensatory masculine responding as a function of sex role. *Journal of Consulting and Clinical Psychology, 47*(2), 252-257.
- Bangsberg, D. R. (2006). Less than 95% adherence to nonnucleoside reverse-transcriptase inhibitor therapy can lead to viral suppression. *Clinical Infectious Diseases, 43*(7), 939-941.
- Bartos, M., & McDonald, K. (2000). HIV as identity, experience or career. *AIDS Care, 12*(3), 299-306. doi: 10.080/095400120050042954
- Beach, M. C., Duggan, P. S., & Moore, R. D. (2007). Is patients' preferred involvement in health decisions related to outcomes for patients with HIV?. *Journal of General Internal Medicine, 22*(8), 1119-1124.
- Becker, A.E., Franko, D.L., Speck, A., & Herzog, D.B. (2003). Ethnicity and differential access to care for eating disorders. *International Journal of Eating Disorders, 33*(2), 205-212.
- Bem, S. L. (1981). *Bem Sex Role Inventory: Professional manual*. Palo Alto, CA: Consulting Psychologists Press.
- Blanch, J., Rousaud, A., Martinez, E., De Lazzari, E., Peri, J. M., Milinkovic, A., ... & Gatell, J. M. (2002). Brief report: Impact of lipodystrophy on the quality of life of HIV-1 infected patients. *JAIDS Journal of Acquired Immune Deficiency Syndromes, 31*(4), 404-407.
- Blouin, A.G., & Goldfield, G.S. (1995). Body image and steroid use in male body builders. *The International Journal of Eating Disorders, 18*(2), 159-165. PMID: 7581418.
- Boisvert, J.A., & Harrell, W.A. (2012). Homosexuality as a risk factor for eating disorder symptomatology in men. *The Journal of Men's Studies, 17*(3), 210-225. doi: 10.3149/jms.1703.210

- Bonnet, E. (2010). New and emerging agents in the management of lipodystrophy in HIV-infected patients. *HIV/AIDS*, 2, 167-178. doi: 10.2147/HIV.S13429
- Bowleg, L. (2011a). Love, sex, and masculinity in sociocultural context: HIV concerns and condom use among African American men in heterosexual relationships. *Men and Masculinities*, 7(2), 166-186. doi: 10.1177/1097184X03257523
- Bowleg, L. (2011b). *The forgotten*. American Psychological Association Psychology and AIDS Exchange Newsletter. Retrieved from <http://www.apa.org/pi/aids/resources/exchange/2011/04/forgotten.aspx>
- Bowleg, L. (2012). The problem with the phrase women and minorities: Intersectionality, an important theoretical framework for public health. *American Journal of Public Health*, 102, 1267-1273. doi: 10.2105/AJPH.2012.300750
- Bowleg, L., Teti, M., Massie, J.S., Patel, A., Malebranche, D. J., & Tschann, J.M. (2011). What does it take to be a man? What is a real man?: Ideologies of masculinity and sexual risk among Black heterosexual males. *Culture, Health & Sexuality: An International Journal for Research, Intervention and Care*, 13(5), 545-559. doi: 10.1080/13691058.2011.55620
- Brashers, D. E., Neidig, J. L., Cardillo, L. W., Dobbs, L. K., Russell, J. A., & Haas, S. M. (1999). "In an important way, I did die": Uncertainty and revival in persons living with HIV or AIDS. *AIDS Care*, 11, 201-219. doi:10.1080/09540129948090
- Brocki, J.M., & Wearden, A.J. (2006). A critical evaluation of the use of interpretative phenomenological analysis (IPA) in health psychology. *Psychology and Health*, 21(1), 87-108. doi:10.1080/14768320500230185
- Brooks, R.A., Etzel, M.A., Hinojos, E., Henry, C.L., & Perez, M. (2005). Preventing HIV among

- Latino and African American gay and bisexual men in a context of HIV related stigma, discrimination, and homophobia: Perspectives of providers. *AIDS Patient Care and STDs*, 19(11), 737-744. doi:10.1089/apc.2005.19.737
- Brooks, D., & Herbert, L. (2006). Gender, race, and media representation. In B. Dow, & J. Wood (Eds.), *The SAGE handbook of gender and communication* (pp. 297-319). Thousand Oaks, CA: SAGE Publications, Inc. doi: 10.4135/9781412976053.n16
- Burgoyne, R., Collins, E., Wagner, C., Abbey, S., Halman, M., Nur, M., & Walmsley, S. (2005). The relationship between lipodystrophy-associated body changes and measures of quality of life and mental health for HIV positive adults. *Quality of Life Research*, 14, 981-990. doi: 10.1007/s11136-004-2580-2
- Burgoyne, R.W., & Saunders, D.S. (2000). Perceived support in newly registered HIV/AIDS clinic outpatients. *AIDS Care*, 12(5), 643-650. doi: 10.1080/095401200750003815
- Burlew, A.K., Feaster, D., Brecht, M.L., & Hubbard, R. (2009). Measurement and data analysis in research addressing health disparities in substance abuse. *Journal of Substance Abuse Treatment*, 36, 25-43.
- Butler, J. (1998). Performative acts and gender constitution: An essay in phenomenology and feminist theory. *Theatre Journal*, 40(4), 519-531.
- Cachelin, F.M., Rebeck, R.M., Chung, G.H., & Pelayo, E. (2002). Does ethnicity influence body size preference? A comparison of body image and body size. *Obesity Research*, 10(3), 158-166.
- Cafri, G., Thompson, J.K., Ricciardelli, L., McCabe, M., Smolak, L., & Yesalis, C. (2005). Pursuit of the muscular ideal: Physical and psychological consequences and putative risk factors. *Clinical Psychology Review*, 25, 215-239. doi: 10.1016/j.cpr.2004.09.003

- Carr, A. (2012). Lipodystrophy: Prevalence and pathogenesis. [Supplemental material].
Infectious Disease News, February 2012, 3-7.
- Carr, A., Emery, S., Law, M., Puls, R., Lundgren, J., & Powderly, W. (2003). An objective case definition of lipodystrophy in HIV infected adults: A case control study. *The Lancet, 361*(9359), 726-735.
- Cash, T.F., & Fleming, E.C. (2002). The impact of body image experiences: development of the body image quality of life inventory. *International Journal of Eating Disorders, 31*(4), 455-460.
- Centers for Disease Control and Prevention. (1982). A cluster of Kaposi's Sarcoma and carinii Pneumonia among homosexual residents of Los Angeles and Orange Counties, California. *MMWR Weekly Report, 31*(23), 305-307. Retrieved from <http://www.cdc.gov/mmwr/preview/mmwrhtml/00001114.htm>
- Centers for Disease Control and Prevention. (1983). Current trends prevention of Acquired Immune Deficiency Syndrome (AIDS): Report of inter-agency recommendations. *MMWR Weekly Report, 32*, 101-103. Retrieved from <http://www.cdc.gov/mmwr/preview/mmwrhtml/00001257.htm>
- Centers for Disease Control and Prevention. (2009). Incidence and diagnoses of HIV infection – Puerto Rico, 2009. *MMWR Weekly Report, 58*, 589-591.
- Centers for Disease Control and Prevention. (2010). Diagnoses of HIV Infection and AIDS in the United States and dependent areas, 2009. *HIV/AIDS Surveillance Report, 21*.
- Centers for Disease Control and Prevention. (2011). *HIV Surveillance by Race/Ethnicity*. Retrieved from http://www.cdc.gov/hiv/pdf/statistics_surveillance_raceEthnicity.pdf

- Centers for Disease Control and Prevention. (2014). *HIV Among African Americans*. Retrieved from <http://www.cdc.gov/nchhstp/newsroom/docs/CDC-HIV-AA-508.pdf>
- Chapman, E. (2000). Conceptualisation of the body for people living with HIV: Issues of touch and contamination. *Sociology of Health and Illness*, 22(6), 840-857.
- Chapman, L. (1998). Body image and HIV: Implications for support and care. *AIDS Care*, 10(2), 179-189. doi: 10.1080/0954012985012480
- Charmaz, K. (1994). Identity dilemmas of chronically ill men. *The Sociological Quarterly*, 35(2), 269-288.
- Ciesla, J. A., & Roberts, J. E. (2001). Meta-analysis of the relationship between HIV infection and risk for depressive disorders. *American Journal of Psychiatry*, 158(5), 725-730.
- Cochrane, J. (2003). The experience of uncertainty for individuals with HIV/AIDS and the palliative care paradigm. *International Journal of Palliative Nursing*, 9, 382-388.
- Collins, E., Wagner, C., & Walmsley, S. (2000). Psychosocial impact of the, lipodystrophy syndrome in HIV infection. *The AIDS Reader*, 10(9), 546-550.
- Cournos, F., & McKinnon, K. (2008). Epidemiology of psychiatric disorders associated with HIV and AIDS. *Comprehensive Textbook of AIDS Psychiatry*, 39-48.
- Connell, R.W. (1995). *Masculinities*. Berkley, CA: University of California Press.
- Courtenay, W.H. (2011). *Dying to be men: Psychosocial, environmental, and behavioral directions in promoting the health of men and boys*. New York, NY: Routledge Taylor Francis Group.
- Corless, I.B., Nicholas, P.K., McGibbon, C.A., & Wilson, C. (2004). Weight change, body image, and quality of life in HIV disease. *Applied Nursing Research*, 17(4), 292-296.

- Crane, H. M., Grunfeld, C., Harrington, R. D., Uldall, K. K., Ciechanowski, P. S., & Kitahata, M. M. (2008). Lipoatrophy among HIV-infected patients is associated with higher levels of depression than lipohypertrophy. *HIV Medicine, 9*(9), 780-786.
- Cusick, L., & Rhodes, T. (1999). The process of disclosing positive HIV status: Findings from qualitative research. *Culture, Health, and Sexuality, 1*(1), 3-18.
- Dageid, W., Govender, K., & Gordon, S.F. (2012). Masculinity and HIV disclosure among heterosexual South African men: Implications for HIV/AIDS interventions. *Culture, Health & Sexuality, 14*(8), 925-940.
- Davies, B., & Harre, R. (1998). Positioning and personhood. In R. Harre & L. van Langenhove (Eds.), *Positioning theory* (pp. 32-52). Oxford: Blackwell.
- Davison, S. P., Timpone, J., Jr., & Hannan, C. M. (2007). Surgical algorithm for management of HIV lipodystrophy. *Plastic and Reconstructive Surgery, 120*, 1843–1858.
doi:10.1097/01.prs.0000267341.14550.a7
- Demarest, J. & Allen, R. (2000). Body image: Gender, ethnic and age difference. *The Journal of Social Psychology, 40*(4), 465-472.
- Duran, S., Saves, M., Spire, B., Cailleton, V., Sobel, A.,...APROCO Study Group. (2001). Failure to maintain long-term adherence to highly active antiretroviral therapy: The role of lipodystrophy. *AIDS, 15*(18), 2441-2444.
- Dworkin, S.L., Fullilove, R.E., & Peacock, D. (2009). Are HIV/AIDS prevention interventions for heterosexually active men in the United States gender specific? *American Journal of Public Health, 99*(6), 981-984.

- Elwy, A.R., Hart, G.J., Hawkes, S., & Petticrew, M. (2002). Effectiveness of interventions to prevent sexually transmitted infections and human immunodeficiency virus in heterosexual men. *Archives of Internal Medicine*, *162*, 1818-1830.
- Exner, T.M., Gardos, P.S., Seal, D.W., & Ehrhardt, A.A. (1999). HIV sexual risk reduction interventions with heterosexual men: The forgotten group. *AIDS and Behavior*, *3*(4), 347-358.
- Feldman, M.B., & Meyer, I.H. (2007). Eating disorders in diverse lesbian, gay, and bisexual populations. *International Journal of Eating Disorders*, *40*(3), 218-226. doi: 10.1002/eat.20360
- Fleishman, J.A., & Fogel, B. (1994). Coping and depressive symptoms in people with AIDS. *Health Psychology*, *13*(2), 156-169.
- Fredrickson, B. L., & Roberts, T. A. (1997). Objectification theory: Towards understanding women's lived experience and mental health risks. *Psychology of Women Quarterly*, *21*(2), 173-206. doi: 10.1111/j.1471-6402.1997.tb00108.x
- Fredrickson, B. L., Roberts, T. A., Noll, S. M., Quinn, D. M., & Twenge, J. M. (1998). That swimsuit becomes you: Sex differences in self-objectification, restrained eating, and math performance. *Journal of Personality and Social Psychology*, *75*(1), 269-284.
- Gagnon, M., & Holmes, D. (2008). Moving beyond biomedical understanding of people living with HIV/AIDS. *Research and Theory for Nursing Practice*, *22*(4), 228-240. doi: 10.1891/0889-7182.22.4.228
- Gagnon, M., & Holmes, D. (2011). Bodies in mutation: Understanding lipodystrophy among women living with HIV/AIDS. *Research and Theory for Nursing Practice: An International Journal*, *25* (1), 23-37. doi: 10.1891/0889-7182.25.1.23

- Gerstmann, J. (1958). Psychological and phenomenological aspects of disorders of the body image. *Journal of Nervous and Mental Disease*, 126(6), 499-512.
- Goffman, E. (1963). *Stigma: Notes on the management of spoiled identity*. New York: Simon & Schuster.
- Gough, H.F. (1957). *California Psychological Inventory*. Palo Alto, CA: Consulting Psychologists Press.
- Gould, S.J. (1996). *The mismeasure of man*. New York: W.W. Norton & Company.
- Grogan, S. (2006). Body image and health: Contemporary perspectives. *Journal of Health Psychology*, 11(4), 523-530. doi: 10.1177/1359105306065013
- Halkitis, P.N., Green, K.A., & Wilton, L. (2007). Masculinity, body image, and sexuality in HIV-seropositive gay men: A two phase formative behavioral investigation using the internet. *International Journal of Men's Health*, 3(1), 27-42. doi: 10.3149/jmh.0301.07
- Helms, J.E. (1996). Toward a methodology for measuring and assessing racial as distinguished from ethnic identity. *Multicultural Assessment in Counseling and Clinical Psychology*, 8, 143-192. Retrieved from <http://digitalcommons.unl.edu/burosbooksmulticultural/8>
- Helms, J.E., Jernigan, M., & Mascher, J. (2005). The meaning of race in psychology and how to change it. *American Psychologist*, 60(1), 27-36. doi: 10.1037/0003-066X.60.1.27
- Higgins, J.A., Hoffman, S., & Dworkin, S.L. (2010). Rethinking gender, heterosexual men, and women's vulnerability to HIV/AIDS. *American Journal of Public Health*, 100(3), 435-445. doi: 10.2105/AJPH.2009.159723
- Hoang, T., Goetz, M. B., Yano, E. M., Rossman, B., Anaya, H. D., Knapp, H., ... Asch, S. M. (2009). The impact of integrated HIV care on patient health outcomes. *Medical Care*, 47(5), 560-567. doi:10.1097/MLR.0b013e31819432a0

- Hospers, H.J., & Jansen, A. (2005). Why homosexuality is a risk factor for eating disorders in males. *Journal of Social and Clinical Psychology, 24*(8), 1188-1201. doi: 10.1521/jscp.2005.24.8.1188
- Huang, J.S., Lee, D., Becerra, K., Santos, R., Barber, E., & Matthews, W.C. (2006a). Body image in men with HIV. *AIDS Patient Care and STDs, 20*, 668-676. doi:10.1089/apc.2006.20.668
- Huang, J.S., Harrity, S., Lee, D., Becerra, K., Santos, R., & Matthews, W.C. (2006b). Body image in women with HIV: a cross-sectional evaluation. *AIDS Research and Therapy, 3*(17), 1-7. doi: 10.1186/1742-6405-3-17
- Human Rights Watch. (2011). *Rights at risk: State response to HIV in Mississippi*. Retrieved from <http://www.hrw.org>. ISBN 1-56432-745-0
- Institute of National Medicine of the National Academies. (2012). *Sex specific reporting of scientific research: A workshop summary*. Washington, DC: National Academies Press.
- Institute of Medicine, National Academy of Sciences, Subcommittee on Standardized Collection of Race/Ethnicity Data for Healthcare Quality. (2009). *Race, Ethnicity, and Language Data: Standardization of health care quality improvement*. Retrieved from <http://www.iom.edu/Reports/2009/RaceEthnicityData.aspx>
- IRN Plus News, Global HIV/AIDS News Analysis. (2008, June). *Africa mind your language: A short guide to HIV/AIDS slang*. Retrieved from <http://www.plusnews.org/Report/78809/AFRICA-Mind-your-language-a-short-guide-to-HIV-AIDS-slang>
- Joffe, H. (1995). Social representations of AIDS: Towards encompassing issues of power. *Papers on Social Representations, 4*(1), 1-40. Retrieved from

http://eprints.lse.ac.uk/24974/1/Social_representations_of_AIDStowards_encompassing_issues_of_power_%28LSERO%29.pdf

- Juhasz, A. (1993). Women and AIDS: Psychological perspectives. In C. Squire (Ed.), *Knowing AIDS through the televised science documentary* (pp. 145-157). London, England: Sage Publications.
- Kadushin, G. (1999). Barriers to social support and support received from their families of origin among gay men with HIV/AIDS. *Health & Social Work, 24*(3), 198-209.
- Kaira, S., Kaira, B., Agrawal, N., & Unnikrishnan, A.G. (2011). Understanding diabetes in patients with HIV/AIDS. *Diabetology & Metabolic Syndrome, 3*(2), 2-7.
- Kaiser Family Foundation. (2013). *The HIV/AIDS epidemic in the United States*. Retrieved from <http://kff.org/hivaids/fact-sheet/the-hivaids-epidemic-in-the-united-states/>
- Kaminski, P.L., Chapman, B.P., Haynes, S.D., & Own, L. (2005). Body image, eating behaviors, and attitudes toward exercise in gay and straight men. *Eating Behaviors, 6*, 179-187.
- Kotler, D.P., Rosenbaum, K., Wang, J., & Pierson, R.N. (1999). Studies of body composition and fat distribution in HIV-infected and control subjects. *Journal of Acquired Immune Deficiency Syndromes & Human Retrovirology, 20*(3), 228-237.
- Kremer, H., Bader, A., O Cleirigh, C., Bierhoff, H. W., & Brockmeyer, N. H. (2004). The decision to forgo antiretroviral therapy in people living with HIV-compliance as paternalism or partnership?. *European Journal of Medical Research, 9*(2), 61-70.
- Larkin, M., Watts, S., & Clifton, E. (2006). Giving voice and making sense in interpretative phenomenological analysis. *Qualitative Research in Psychology, 3*, 102-120. doi: 10.1191/1478088706qp062oa

- Leit, R.A., Pope, H.G., & Gray, J.J. (2000). Cultural expectations of muscularity in men: The evolution of the playgirl centerfolds. *International Journal of Eating Disorders*, 29(1), 90-93.
- Leit, R.A., Gray, J.J., & Pope, H.G. (2002). The media's representation of the ideal male body: A cause for muscle dysmorphia. *International Journal of Eating Disorders*, 31(3), 334-338. doi: 10.1002/eat.10019.
- Lima, V. D., Bangsberg, D. R., Harrigan, P. R., Deeks, S. G., Yip, B., Hogg, R. S., & Montaner, J. S. G. (2010). Risk of viral failure declines with duration of suppression on HAART, irrespective of adherence level. *Journal of Acquired Immune Deficiency Syndromes (1999)*, 55(4), 460–465. doi:10.1097/QAI.0b013e3181f2ac87
- Lincoln, Y.S., & Guba, E.A. (2000). Paradigmatic controversies, contradictions, and emerging confluences. In N.K. Denzin & Y.S. Lincoln (Eds.), *The handbook of qualitative research* (2nd ed., pp. 163-188). Beverly Hills, CA: Sage.
- Loue, S. (2006). Preventing HIV, eliminating disparities among Hispanics in the United States. *Journal of Immigrant Health*, 8, 313-318.
- Majors, R. & Billson, J.M. (1992). *Cool pose: The dilemmas of black manhood in America*. New York: Touchstone.
- Martinez, S., Kemper, C.A., Diamond, C., Wagner, G., & the California Collaborative Treatment Group. (2005). Body image in patients with HIV/AIDS: Assessment of a new psychometric measure and its medical correlates. *AIDS Patient Care*, 19(3), 150-155. PMID: 15798382

- Martins, Y., Tiggerman, M., & Kirkbride, A. (2007). Those Speedos become them: The role of self-objectification in gay and heterosexual men's body image. *Personality and Psychology Bulletin, 33*(5), 634-647. doi: 10.1177/0146167206297403
- Mays, V.M., So, B.T., Cochran, S.D., Detels, R., Benjamin, R., Allen, E., & Kwon, S. (2001). HIV disease in ethnic minorities: Implications for racial/ethnic difference in disease susceptibility and drug dosage response for HIV infection and treatment. In A. Baum, T.A. Revenson, & J.E. Singer. (Eds.), *Handbook of Health Psychology* (pp. 801-816). Mahwah, NJ: Lawrence Erlbaum Associates.
- McCreary, D.R., Saucier, D.M., & Courtenay, W.H. (2005). The drive for muscularity and masculinity: Testing associations among gender-role traits, behaviors, attitudes, and conflict. *Psychology of Men and Masculinity, 6*(2), 83-94. doi: 10.1037/1524-9220.6.2.83
- McCreary, D.R., Hildebrandt, T.B., Heinberg, L.J., Boroughs, M., & Thompson, J.K. (2007). A review of body image influences on men's fitness goals and supplement use. *American Journal of Men's Health, 1*(4), 307-316. doi 10.1177/1557988306309408.
- Messerschmidt, J.W. (1993). *Masculinities and crime: Critique and reconceptualization of theory*. Lanham, MD: Rowman & Littlefield Publishers.
- Morrow, S.L. (2005). Quality and trustworthiness in qualitative research in counseling psychology. *Journal of Counseling Psychology, 52*(2), 250-260. doi: 10.1037/0022-0167.52.2.250
- Mosquera, P. M. R. (2011). Masculine and feminine honor codes. *Revista de Psicología Social, 26*(1), 63-72.
- Murray Parkes, C. (1973). Factors determining the persistence of phantom pain in the amputee. *Journal of Psychosomatic Research, 17*(2), 97-108.

- Oates, T.P., & Durham, M. G. (2004). The mismeasure of masculinity: The male body, 'race,' and power in the enumerative discourses of the NFL draft. *Patterns of Prejudice*, 38(3), 301-323. doi: 10.1080/0031322042000250475
- Olivardia, R., Pope, H.G., Jr., Mangweth, B., & Hudson, J.I. (1995). Eating disorders in college men. *American Journal of Psychiatry*, 152(9), 1279-1285.
- Patton, M.Q. (1990). *Qualitative evaluation and research method*. (2nd ed.). Newbury Park, CA: Sage Publications.
- Pennsylvania Recovery and Resiliency. (2014). *Medicaid-funded peer support services in Pennsylvania frequently asked questions*. Retrieved from http://www.parecovery.org/documents/PSS_FAQ_110114.pdf
- Persson, A. (2004). Incorporating pharmakon: HIV, medicine, and body shape change. *Body and Society*, 10(4), 45-67. doi: 10.1177/1357034X04047855.
- Persson, A. (2005). Facing HIV: Body shape change and the (in)visibility of illness. *Medical Anthropology*, 24, 237-264. doi: 10.1080/0459740500182683.
- Persson, A., & Newmann, C. (2008). Making monsters: Heterosexuality, crime and race in Western media coverage of HIV. *Sociology of Health & Illness*, 30(4), 632-646. doi: 10.1111/j.1467-9566.2008.01082.x
- Persson, A., & Richards, W. (2008). From closet to heterotopia: A conceptual exploration of disclosure and 'passing' among heterosexuals living with HIV. *Culture, Health & Sexuality*, 10(1), 73-86. doi: 10.1080/13691050701669048
- Plankey, M., Bacchhetti, P., Jin, C., Grimes, B., Hyman, C., ... Tien, P.C. (2009). Self-perception of body fat changes and HAART adherence in the women's interagency HIV study. *AIDS Behavior*, 13, 53-59. doi: 10.1007/s10461-008-9444-7

- Pope, H.G., Gruber, A.J., Mangweth, B., Bureau, B., deCol, C., Jouvent, R., & Hudson, J.I. (2000). Body image perceptions of men in three countries. *American Journal of Psychiatry*, 157(8), 1297-1301. doi: 10.1176/appi.ajp.157.8.1297
- Pope, H.G., Olivardia, R., Gruber, A., & Borowiecki, J. (1998). Evolving ideals of male body image as seen through action toys. *International Journal of Eating Disorders*, 26(1), 65-72.
- Proctor, V.E., Tesfa, A., & Tompkins, D.C. (1999). Barriers to adherence in highly active antiretroviral therapy as expressed by people living with HIV/AIDS. *AIDS Patient Care and STDs*, 13(9), 535-544. PMID: 10813033
- Pyke, K.D. (1996). Class-based masculinities: The interdependence of gender, class, and interpersonal power. *Gender and Society*, 10(5), 527-549.
- Rabkin, J. G. (2008). HIV and depression: 2008 review and update. *Current HIV/AIDS Reports*, 5(4), 163-171.
- Raj, A., & Bowleg, L. (2012). Heterosexual risk for HIV among black men in the United States: A call to action against a neglected crisis in black communities. *American Journal of Men's Health*, 6(3), 178-181. doi: 10.1177/1557988311416496
- Remien, R. H., Hirky, A. E., Johnson, M. O., Weinhardt, L. S., Whittier, D., & Le, G. M. (2003). Adherence to medication treatment: A qualitative study of facilitators and barriers among a diverse sample of HIV+ men and women in four US cities. *AIDS and Behavior*, 7(1), 61-72.
- Reynolds, N.R., Neidig, J.L., Wu, A.W., Gifford, A.L., & Holmes, W.C. (2006). Balancing disfigurement and fear of disease progression: Patient perceptions of HIV body fat redistribution. *AIDS CARE*, 18(7), 663-673. doi:10.1080/09540120500287051

- Russell, C.J., & Keel, P.K. (2002). Homosexuality as a specific risk factor for eating disorders in men. *International Journal of Eating Disorders*, 31(3), 300-306. doi: 10.1002/eat.10036
- Sansone, R.A., Sansone, L.A., Gaither, G.A., & Morris, J.L. (2004). Patient attitudes toward weight gain with medications. *General Hospital Psychiatry*, 26(6), 487-489.
- Santos, C.P., Felipe, Y.X., Braga, P.E., Ramos, D., Lima, R.O., & Segurado, A.C. (2005). Self-perception of body changes in persons living with HIV/AIDS: Prevalence and associated factors. *AIDS*, 19(4), 14-21.
- Sax, P. (2012). Diagnosing HIV lipodystrophy. [Supplemental material]. *Infectious Disease News*, February 2012, 8-9.
- Scanavino, M. D. T. (2011). Sexual dysfunctions of HIV-positive men: Associated factors, pathophysiology issues, and clinical management. *Advances in Urology*, 2011, 1-10. doi:10.1155/2011/854792
- Schilder, A. J., Kennedy, C., Goldstone, I. L., Ogden, R. D., Hogg, R. S., & O'Shaughnessy, M. V. (2001). "Being dealt with as a whole person." Care seeking and adherence: the benefits of culturally competent care. *Social Science & Medicine*, 52(11), 1643-1659.
- Sculptra Patient Access Program. (2015). Retrieved from <https://www.rxhope.com/PAP/pdf/scupae1039.pdf>
- Schwartz, J.P., Grammas, D.L., Sutherland, R.J., Siffert, K.J., & Bush-King, I. (2010). Masculine gender roles and differentiation: Predictors of body image and self-objectification in men. *Psychology of Men & Masculinity*, 11(3), 208-224. doi: 10.1037/a0018255

- Seal, D.W., & Ehrhardt, A.A. (2004). HIV-prevention-related sexual health promotion for heterosexual men in the United States: Pitfalls and recommendations. *Archives of Sexual Behavior, 33*(3), 211-222.
- Seidl, E.M.F., & Machado, A.C.A. (2008). Bienestar psicologico, afrontamiento y lipodistrofia en personas que viven con VIH/SIDA. *Psicologia em Estudo, 13*(2), 239-247. doi: 10.1590/s1413-73722008000200006
- Sharma, A., Howard, R.S., Klein, E.E., Schoenbaum Buono, D., & Webber, M.P. (2007). Body image in older men with or at risk for HIV infection. *AIDS Care, 19*(2), 235-245.
- Silvestre, A. J., Hylton, J. B., Johnson, L. M., Houston, C., Witt, M., Jacobson, L., & Ostrow, D. (2006). Recruiting minority men who have sex with men for HIV research: Results from a 4-city campaign. *American Journal of Public Health, 96*(6), 1020–1027. doi:10.2105/AJPH.2005.072801
- Sippelle, C.R., Ascough, J.C., Detrio, D.M., & Horst, P.A. (1977). Neuroticism, extroversion, and response to stress. *Behavior, Research, and Therapy, 15*(5), 411-418.
- Smith, J.A., Flowers, P., & Larkin, M. (2013). *Interpretative phenomenological analysis: Theory, method, and research*. Thousand Oaks, CA: Sage.
- Smith, J.A., & Osborn, M. (2008). Interpretative phenomenological analysis. In J.A. Smith (Ed.), *Qualitative psychology: A practical guide* (pp.53-80). Thousand Oaks, CA: Sage.
- Steel, J.L., Landsittel, D., Calhoun, B., Wieand, S., & Kingsley, L.A. (2006). Effects of lipodystrophy quality of life and depression in HIV-infected men on HAART. *AIDS Patient Care and STDs, 20*(8), 565-575.
- Stoff, D. M., Mitnick, L., & Kalichman, S. (2004). Research issues in the multiple diagnoses of HIV/AIDS, mental illness and substance abuse. *AIDS Care, 16*(1), 1-5.

- Stone, V. E. (2004). Optimizing the care of minority patients with HIV/AIDS. *Clinical infectious diseases*, 38(3), 400-404.
- Stone, V.E., Jordon, J., Tolson, J., Miller, R., & Pillon, T. (2004). Perspectives on adherence and simplicity for HIV-infected patients on antiretroviral therapy: self-report of the relative importance of multiple attributes of highly active antiretroviral therapy (HAART) regimens in predicting adherence. *Journal of Acquired Immune Deficiency Syndrome*, 36(3), 808-816.
- Striegel-Moore, R.H., Silberstein, L.R., & Rodin, J. (1986). Toward an understanding of risk factors for bulimia. *American Psychologist*, 41(3), 246-263. doi:10.1037/003-066X.41.3.246
- Stunkard, A.J., Sorenson, T., & Schlusinger, F. (1983). The Danish adoption register study for the study of obesity and thinness. In S.S. Kety, L.P. Rowland, R.L. Sidman, & S.W. Matthysse (Eds.), *The genetics of neurological and psychological disorders* (pp. 115-120). New York: Raven Press.
- Substance Abuse and Mental Health Services Administration/SAMHSA. (2009). *What Are Peer Recovery Support Services?* Rockville, MD. Retrieved from <http://store.samhsa.gov/product/What-Are-Peer-Recovery-Support-Services-/SMA09-4454>
- Sullivan, P.S., McNaghten, A.D., Begley, E., Hutchinson, A., & Cargill, V.A. (2007). Enrollment in racial/ethnic minorities in clinical research studies of HIV medications. *Journal of National Medical Association*, 99(3), 242-250.
- Tanna, N., Venturi, M. L., & Olding, M. (2005). Correction of lipodystrophy in HIV-positive patients: Surgeon beware. *Plastic and Reconstructive Surgery*, 116(3), 136.

- Tate, H., & George, R. (2001). The effect of weight loss on body image in HIV positive gay men. *AIDS Care, 13*(2), 163-169.
- Thompson, J.K. (1990). *Body image disturbance, assessment, and treatment*. New York, NY: Pergamon Press.
- Tien, P.C., & Grunfield, C. (2004). What is lipodystrophy? Defining fat distribution changes in HIV infection. *Current Opinion in Infectious Disease, 17*(1), 27-32. doi: 10.1097/01.qco.000113645.87565.41
- Turner, D.C. (1995). HIV, body image, and sexuality. *AIDS Patient Care, 9*(5), 245-248. PMID: 11361405
- Varas-Diaz, N., Toro-Alfonso, J., & Serrano-Garcia, I. (2005). My body, my stigma: Body interpretations in a sample of people living with HIV/AIDS in Puerto Rico. *The Qualitative Report, 10*(1), 122-142.
- Vella, M. M. (2015). The unknown/The unanticipated: A surgical journey of correcting HIV-related abdominal lipodystrophy. *Qualitative Health Research*. Advance online publication. doi: 10.1177/1049732315570126
- Vera, E. M., & Speight, S. L. (2003). Multicultural competence, social justice, and counseling psychology: Expanding our roles. *The Counseling Psychologist, 31*(3), 253-272. doi: 10.1177/0011000003031003001
- West, C., & Zimmerman, D.H. (1987). Doing gender. *Gender & Society, 1*(2), 125-151. doi: 10.1177/0891243287001002002
- Wohl, A.R., Johnson, D.F., Lu, S., Jordan, W., Beall, G., Currier, J., & Simon, P.A. (2002). HIV risk behaviors among African American men in Los Angeles county who self-identify as heterosexual. *Journal of Acquired Immune Deficiency Syndromes, 31*, 354-360.

- Wong, W.T., & Ussher, J.M. (2008). Life with HIV and AIDS in the era of effective treatments: 'It's not just about living longer!'. *Social Theory & Health*, 6, 117-131. doi: 10.1057.sth.2008.4
- Van Der Straten, A., Vernon, K. A., Knight, K. R., Gomez, C. A., & Padian, N. S. (1998). Managing HIV among serodiscordant heterosexual couples: serostatus, stigma and sex. *AIDS Care*, 10(5), 533-548.
- World Health Organization. (2010). *Developing sexual health programs: A framework for action*. Retrieved from http://www.who.int/reproductivehealth/publications/sexual_health/rhr_hrp_10_22/en/
- Yancey, A. K., Ortega, A. N., & Kumanyika, S. K. (2006). Effective recruitment and retention of minority research participants. *Annual Review of Public Health*, 27, 1-28. doi: 10.1146/annurev.pubhealth.27.021405.102113
- Yeh, C.J., & Inman, A.G. (2007) Qualitative data analysis and interpretation in counseling psychology: Strategies for best practices. *The Counseling Psychologist*, 35(3), 369-403. doi: 10.1177/0011000006292596.
- Zivi, K. (1998). Gendered epidemic: Representations of women in the age of AIDS. In N. L. Roth & K. Hogan (Eds.), *Constituting the clean and proper body: Convergences between abjection and AIDS* (pp. 33-62). New York, NY: Routledge.

Table 1. *Demographic characteristics of participants.*

Characteristic	Participants (<i>n</i> = 21)	%
Disease status		
HIV positive	8	38.1%
AIDS defined	13	61.9%
Years living with disease	Range = 3-33 years Mean = 15.7 years	
Take medications as prescribed		
Yes	16	76.2%
No	4	23.8%
Number of participants reporting missing doses	11	52.4%
Estimation of missed doses		
1-2	6	54.5%
3-4	1	9.1%
4-5	2	18.2%
8 and over	2	18.2%
Age		
	Range = 23-67 years Mean = 48 years	
Up to 30 years	2	9.5%
31-40 years	1	4.8%
41-50 years	11	52.5%
51 years or more	7	33.3%
Weight (self-report)	Range = 128-268 pounds Mean = 188 pounds	
Height (self-report)	Range = 5 ft 3 in – 6 ft 3 in	
Relationship status		
Single	13	61.9%
Married	3	14.3%
Separated	3	14.3%
Divorced	1	4.8%
Widower	0	
In a relationship	1	4.8%

(table continues)

Table 1, continued

Characteristic	Participants (<i>n</i> = 21)	%
Skin color		
Canella (English translation: cinnamon)	1	
Black	5	23.8%
Black Africa	1	
Brown	4	19.0%
Dark	1	
Dark Brown	1	
Light	1	
Light Brown	1	
Olive	1	
Reddish	1	
Tan	3	14.3%
White	1	
Identity		
African American	3	14.3%
African Native	6	28.6%
Kenya	2	
Nigeria	1	
Zimbabwe	1	
Ghana	2	
Hispanic (all identifying as from Puerto Rico)	6	28.6%
Latino	2	9.5%
Puerto Rico	1	
Dominican Republic	1	
Native Pacific or Hawaiian Islander (Identifying as from Honolulu)	1	4.8%
Mixed Identity	3	14.3%
African American and American Indian	1	
African American and Dominican	1	
Irish, Canadian Indian, and Ethiopian	1	

(table continues)

Table 1, continued

Characteristic	Participants (<i>n</i> = 21)	%
Primary Language		
English	16	76.2%
Spanish	2	9.5%
African language	3	14.3%
Akan	1	
Luo	1	
Swahili	1	
Secondary Language		
None	6	28.6%
English	4	19.0%
Spanish	7	33.3%
Portuguese	1	4.7%
African language	3	14.3%
Ga Tsi	1	
Swahili	1	
Yoruba	1	
Educational level		
Elementary or primary school	2	9.5%
Some high school	2	9.5%
GED	3	14.3%
High school diploma	4	19.0%
Vocational school	2	9.5%
Some college	3	14.3%
Associate degree	1	4.7%
Undergraduate degree	2	9.5%
Some graduate coursework	1	4.7%
Employment status		
Employed	6	28.6%
Unemployed	15	71.4%
Income level		
Under \$20,000	17	80.9%
\$20,000-\$39,000	2	9.5%
\$40,000-\$59,000	1	4.7%
\$80,000-\$99,999	1	4.7%

Table 2. *Body Image Questionnaire results.*

Question or Category	Participants	%
	<i>n</i> = 21	
a.) Do you exercise regularly?		
Yes	11	52.4%
No	10	47.6%
If so, what type of exercise?		
*walking		
*running		
*weight lifting		
If so, how long do you exercise?		
Range = 0-840min		
Mean = 155min		
b.) Are you able to afford a gym membership?		
Yes	11	52.4%
No	10	47.6%
c.) Do you feel that you eat a healthy/balanced diet?		
Yes	11	52.4%
No	10	47.6%

d.) Do you feel as if you could eat better?

Yes	11	52.4%
No	10	47.6%

If you checked “yes”, what do you think you could do to improve your diet? :

*being able to have enough money to buy fruits, vegetables, and protein (i.e., meat)

*having more money to eat 2-3 meals per day

*eat more healthful foods such as fruit, vegetables, and meat.

e.) Do you have any chronic medical conditions that you were diagnosed with by your medical provider aside from HIV? For example, chronic medical conditions may include diagnoses made by your doctor such as diabetes, high blood pressure, thyroid disease, hepatitis C, depression, anxiety.

Yes	14	66.7%
No	7	33.3%

If you checked “yes”, please indicate what other chronic medical conditions :

*hepatitis C

*diabetes type II

*heart disease,

*osteoporosis

*hyperlipidemia

* hypertension

*psychiatric disorders including: bipolar disorder, major depressive disorder, anxiety disorders.

f.) Did you have any surgical cosmetic procedure(s). For example, surgical cosmetic procedures may include liposuction, gastric bypass, lap band, nose job, face lift, peck implants, penis enhancements) before your HIV or AIDS diagnosis?

Yes	0	
No	21	100%

g.) Did you have any surgical cosmetic procedure(s) after your HIV or AIDS diagnosis? For example surgical cosmetic procedures may include, liposuction, gastric bypass, lap band, nose job, face lift, peck implants, penis enhancements.

Yes	4	19%
No	17	81%

If you checked “yes”, please indicate what surgical cosmetic procedures you had done: _____:

*liposuction for HAART induced gynecomastia

*cheek implants and facial fillers for facial wasting

*liposuction for HAART induced buffalo hump

*panniculectomy for excess abdominal skin and fat from HAART.

h.) Would you consider getting a surgical cosmetic procedure for areas of your body that you may dislike if you insurance covered the procedure for you?

Yes	16	76.2%
No	5	23.8%

If you checked “yes”, please indicate what surgical cosmetic procedures you would like to have done:

*facial fillers

*butt implants

*calf implants

*liposuction of chest and peck implants

*liposuction for excess abdominal fat

i.) Did you ever get any facial injections to even out fat loss in your face? This may include Sculptra or Botox?

Yes	1	4.8%
No	20	95.2%

j.) Did you ever inject yourself with a human growth hormone like Serostim to reduce fat in your stomach?

Yes	0	
No	21	100%

k.) Did you ever inject steroids?

Yes	1	4.8%
No	20	95.2%

l.) Did you ever use testosterone replacement? This could come in different forms like gels, skin patches, mouth patches, injections, or implants?

Yes	2	9.5%
-----	---	------

No	19	90.5%
----	----	-------

m.) Do you take dietary supplements to enhance muscle tone such as whey protein powder, creatine powder, or protein bars?

Yes	6	28.6%
-----	---	-------

No	15	71.4%
----	----	-------

n.) Do you have tattoos?

Yes	8	38.1%
-----	---	-------

No	13	61.9%
----	----	-------

If you checked “yes”, how many do you have?

Range = 0-27

Mean = 3.76

o.) Did you get most of these tattoos before or after you were diagnosed with HIV or AIDS?

Before HIV or AIDS	0
--------------------	---

After HIV or AIDS	8	100%
-------------------	---	------

If you got them after your HIV or AIDS diagnosis, what regions of your body did you get them on?

*hands	2
--------	---

*wrist	1
--------	---

*face	0
-------	---

*arm	7
------	---

*chest/abdomen region	5
-----------------------	---

*thigh	1
--------	---

*calf	1
-------	---

*back 3

p.) Do you shave your hair on areas aside from your face and neck?

Yes 14 66.7%

No 7 33.3%

If you checked “yes”, please place a check next to what body parts or areas you shave:

*under arms/armpit 11

*arms 3

*chest 6

*legs 1

*pubic or genital 11

*other 3

Table 3. *Perceived Lipodystrophy Scale results.*

<i>Body Part</i>	<i>Participants</i>	<i>%</i>
	<i>n</i> = 21	
Total PLS Score	Range = 0-27 Mean = 10	
Number of participants reporting some fat gain or loss	20	95.2%
a.) Face		
Fat Loss	8	38.10%
Mild	3	
Moderate	3	
Extreme	2	
Fat Gain	10	47.62%
Mild	3	
Moderate	4	
Extreme	3	
b.) Under chin		
Fat Loss	5	23.81%
Mild	3	
Moderate	1	
Extreme	1	
Fat Gain	8	38.10%
Mild	3	
Moderate	4	
Extreme	1	
c.) Back of neck		
Fat Loss	2	9.52%
Mild	2	
Moderate	0	
Extreme	0	
Fat Gain	4	19.05%
Mild	3	
Moderate	0	
Extreme	1	

d.) Upper arm

Fat Loss	6	28.57%
Mild	1	
Moderate	4	
Extreme	1	
Fat Gain	6	28.57%
Mild	4	
Moderate	2	
Extreme	0	

e.) Lower arm

Fat Loss	6	28.57%
Mild	4	
Moderate	2	
Extreme	0	
Fat Gain	4	19.05%
Mild	3	
Moderate	1	
Extreme	0	

f.) Abdomen or stomach

Fat Loss	2	9.52%
Mild	0	
Moderate	0	
Extreme	2	
Fat Gain	16	76.19%
Mild	5	
Moderate	6	
Extreme	5	

g.) Chest and/or pecks

Fat Loss	4	19.05%
Mild	2	
Moderate	1	
Extreme	1	
Fat Gain	8	38.10%
Mild	3	
Moderate	3	
Extreme	2	

h.) Upper thigh

Fat Loss	8	38.10%
Mild	2	
Moderate	5	
Extreme	1	
Fat Gain	4	19.10%
Mild	3	
Moderate	1	
Extreme	0	

i.) Lower calves or legs

Fat Loss	7	33.33%
Mild	2	
Moderate	5	
Extreme	0	
Fat Gain	6	28.57%
Mild	4	
Moderate	2	
Extreme	0	

j.) Butt

Fat Loss	8	38.10%
Mild	3	
Moderate	4	
Extreme	1	
Fat Gain	6	28.57%
Mild	4	
Moderate	1	
Extreme	1	

Table 4. Master Theme Table

Super-ordinate theme	Quotation
I. Describing the Valued and Devalued Body	
Valued/devalued shape and size dimensions	
Valued shape and size dimensions (general)	<p>Ain't nobody want no bones.”</p> <p>“bulky”</p> <p>“puffy”</p> <p>“pumped up”</p> <p>“a muscly man”</p> <p>“strong”</p> <p>“sculptured chests”</p> <p>“toned”</p> <p>“carved out”</p> <p>“hard looking”</p>
Valued size dimensions (specific)	<p>Height: over 6 ft</p> <p>Weight: over 200 pounds</p> <p>Waists 34-36 inches</p> <p>“six pack abs”</p>
Language prefacing valued or devalued shape and size dimensions (“should,” “not,” “no”).	<p>P.2: “the legs should not be too hairy or too much without hair, they should not look like toothpicks....the body should look like an athlete, not too skinny and not too fat...the butt should look medium, not too skinny, not too fat.”</p> <p>“no beer belly”</p> <p>“no muffin top.”</p>

P.4: “there should be no flab flopping around. If a man has to pinch an inch then it’s time to do something about that.”

Language pattern of “should,” “not,” “no” with medical providers

P.2: “I could never, ever tell my doctor that I wasn’t taking these meds all the time. He would tell me no, that I couldn’t do that. He’s like my pops [i.e., father].”

P.4: “Every time I get on the scale my doctor screams “no! this weight is no good. You shouldn’t be that heavy.”

P.5: “Doc is about the numbers [referencing his HIV viral load], they should be what he wants them to be.”

Symbolic images of the valued/devalued body

Fantasy characters, heroes, warriors, animals of strength

P.6: “An athletic, heroic body, perfectly built, lots of muscles in a heroic way. Like a superman type of body.”

P.14: “To me a well-built man has muscles in his arms, and what they call these? Six packs? Did you ever see that movie *300*? All those guys had no stomachs. That’s the way that men should look like, the men in that movie. “

P. 19: I got an uncle who used to be a body builder. When you are a body builder that’s not really your body. It doesn’t mean it’s a normal body. He was building his body for competition, for the perfect shape and size. I think he was doing it to be a strong man, as strong as a bull, maybe more than that to be a dominant figure. That is the reason why my uncle was doing it because he wanted to be a

strong man and dominant, like an animal, natural. Like animals, they fight to be dominant. That's a natural instinct you have, to dominate let's say if you're a man. Some men are like women because they don't try to have this shape and size of a man. Let me give you an example of an animal, a lion. That's what I think we should all try to be, a dominant man with our shape and size like my uncle. To want to look like this, this is natural. When you look like a lion, it is like you are saying: "I'm the one, that's my territory." To be like the lion, my uncle had to use steroids. You must do this to become big in shape and size.

Images of the diminishment, loss of strength

P.1: "With all the walking I do, I should have legs like a racehorse and I do not um, my thighs are the size of some people upper arms."

P.1: "People that have known me for years told me I look like an Auschwitz survivor."

P.1: "What can you say? I do look like one. They saw the dramatic weight loss and such. So did I. "

P.12: "I have this wide back, scaly skin, double chin, and this stomach that just hangs. My body looks slow. It feels slow."

P.8: "I felt like each part of my body was a different size. It didn't match. I felt like a guinea pig."

P.8: "walking skeletons"

P.8: "dropping dead like flies."

Comparison of the valued body before
HAART and devalued body after HAART

Before HAART

P.20: “Uh that was in 2005 or 2006, before I was diagnosed. I was at 200 pounds or a little under. I had definition. I wasn’t using. I used to go out and dance. I was in ___[name of 12-step program]. I used to go out with dancing groups, people who tried to stay clean. And they danced and I was like ‘alright, alright, let’s go, let’s go, let’s go.’” I was taking care of myself all around even going to the gym.”

P.21: I was on a power lifting team. I held the record for my size and my weight for ___[number of years]. This was in the state penitentiary. A power lifting team is when they compete and have competitions against other places. You have to work out 5 days a week and work hard to gain strength. I was working out two times a day for two hours, in the mornings and in the afternoons

P.2: “Yes it was when I was in the penitentiary. I was very big, very built, muscly, muscle man. I did ___[number of years] in the penitentiary. I was big. My exercise was different. I did my exercise everyday. I did calisthenics, handball, and I also lifted weights, pull-ups push-ups. That was when my body was at its best. I weighed 230 pounds. It was a lot of weight but it was all muscle.”

P.9: “My body looked like someone in the military. I was 22 years old and in training --- swimming, long distance running, lifting weights. I had 1% body fat. My body showed my routine. I felt proud.”

P.10: “My body could do things that most boys my age couldn’t do. I had a body most boys my age didn’t have. I knew it. I was a top basketball player at __, so I was always training, lifting weights, squats, running, pretty much a full workout. I played basketball 3-4 hours a day. My arms were big, my chest was tight, my legs were bigger, my butt. Everything was bigger and firm because I was in good shape. Not like now.”

After HAART

P.18 [speaking of fat gain and inability to build muscle mass]: “I was taking the medication for about six months when I stepped on the scale at the doctors office, 30 pounds heavier, all in my gut and chin. I was lifting weights and my arms lost all their muscle. I went from a man to looking like a fat boy.”

P.14: “I gained fat where I didn’t want it and now no muscles where I want them. It’s fat though not muscles, fat sloppy.”

P.14: “My stomach and neck are fat...my arms and legs no muscles, just small and fat sloppy. Now I’m this fat puny thing... like what do you call it? An oompa loompa.”

P.13: It limits me a lot. I used to walk two miles to school and now I can't even walk a half-mile without sitting down. My brother and me used to run together. He says to me "I wish your life would be better. I want the old___ [nickname of participant] back." I'm like 'yeah so do I' because he was incarcerated. He went to jail and I was fine. He came back years later and I'm like this. He literally has to carry me up the stairs.

II. Losing and Gaining Control

Routine activities

P.11: "I look in the mirror to shave and I see this face that's sunken in and doesn't look like it's mine. It's hard to look in the mirror. My razor gets caught in the spaces in my face. I always end up bleeding...My blood reminds me of how contagious I am. Then the cuts, they don't heal right. If I didn't have to shave, I won't look in the mirror."

P.14: "Like a month ago, I saw my stomach and these big titties in the mirror for the first time. 'Are these really mine?' I looked like a fat woman.And then no foot. Right away when I saw this I thought, you're gonna die. I went to my bed and started to cry. I never cry. I felt so depressed that I even talked to the nurse."

Intimacy

P.5: "I'm mad at myself. Because I knew this shit was out there and I didn't take the precautions. It's pride, embarrassment, shame, fear. I don't put no curbs on my life other than

sex and touching. I got to consider that I got to deal with things that's unfortunate, take it, roll with the punches. I'm not gonna get anyone else sick besides me. And whatever else happens happens cuz you can't change a damn thing. So um, my dad always told me "I don't care what it is, if you digging a ditch, be the best damn ditch digger in the world." And I always listened to him. You don't want to be there but damn it if you done then go ahead and do the best you can do. And that's the way I was raised. So I will be the best with HIV that I can and that means. No sex, no kissin."

P.7: "How should I say this, what I want to say here? Hmm...when my stomach looks so fat that I can't see my thing [points to his genital region], you don't want to have sex...I try to get out of it as much as possible."

P.10: "I used to have bigger arms and well...like I said before they don't look like at all what they used to be. [name of partner] has bigger arms than me...I find myself making excuses...trying to get out of hugging her....trying to get out of having sex with her cuz' I don't look right holding her with these arms...I look at them sometimes and they make me disgusted...they must make her feel that way too."

P.2: "I took my doctors suggestion to wear padded underwear or put a pillow underneath my butt if I wanted to sit on the couch to cuddle with [name of partner]...It didn't work. I was still in pain."

P.13: "I don't like being touched period. I don't like people touching me...like I yell at people 'don't touch me'...It's just. I don't know....I'm so different. I don't want to be. No one can understand me."

Use of clothing and tattoos

P. 16: “They’ll know. They’ll know and I’ll be rejected. I don’t talk about my body to no one. I just hide it. I wear a lot more baggy clothes since this medicine to hide my body so you can’t notice the AIDS. It’s like when women wear a dress from head to toe. They’re ashamed. Most people who are fat cover their body. Most people who don’t look good cover their body.”

P.20: “Most of my tattoos are after my diagnosis. After I was taking my meds, I went to ___[name of beach] and my stomach was starting to stick out really bad. And I was like ‘look at my tattoos, that’s what you can look at.’”

Engagement with medical care and the community

P.7: “In our African tradition, it’s the men who are supposed to provide for the family...If you don’t feed your family, you’re not a man, that’s what we consider in our culture.”

P.15: “If I didn’t take these pills people would surely know and um there would be lots of different things that happen. I probably would lose my work. My family would be out of the community. My family wouldn’t eat. People only know AIDS and that means skinny, that is death. It is shameful not to belong to your community.”

P.3: “I follow every instructions every drug

that the doctor gives me. You see me. I'm very fit. I'm very strong. I'm not skinny. The HIV does not make me weak. Sometimes I exercise with our teenagers from 18-25. I run more than them. I'm stronger than them. When they ask my age, I just pretend to be on their level because I don't want to explain myself, to answer so many questions. So when they ask my age and they say they are 25, I just say I'm 26. Because I don't want to say that I am 45 when I can run more than them. I can do so many things that they cannot do. The things I can lift, they cannot lift them. And I can see them by the age of 45, they will lose more strength. Even the way they walk, it is not manly."

P. 17: "I decided I would get in the car and get in an accident to kill myself...I wasn't worth anything as a man. I got a horrible body. I have a horrible body. I was no good to society. I was just an outcast. I didn't want to depend on medication... Sometimes I wondered if my doctor would think it was worth living if he looked like this?"

P.4: "My body already looks like a sagging mess from these medications. I'm trying to avoid even more sagging so I do my push ups and curls. The doctor says that if that cage opens back up then they have to reopen me. And I just tell him 'yes' and then keep doing my push-ups and curls."

HAART non-adherence

P.21: "If I go by my doctor, I'm definitely obese. But me, my ideal weight would be 180. My doctor says I should be 160. There is a

fear of looking sick if I'm too fat or too skinny. My doctor doesn't get this."

P.12: "I know for a fact that these medications stop me from getting muscle... I stop them to get my muscle back, to get rid of a little of this [looks down at abdomen] and to get rid of a little of this fat here [touches chin]...I know that I can't do this forever...Like I used to be able to take___ [names two medications] and now I'm resistant so I got to watch with this one a little more."

P.21: "I've had my doctors deny what these medications do. That's ok. I know cuz' I live with me. I know that when I started taking them, my body got destroyed...I know when I stop taking them for a week or two, I lose a few pounds, but then I've got to start them again."

P.21: "Let me think [long pause]. About 4 times a year, one time each season."

III. Navigating Social Dimensions of Visibility and Invisibility

Media representations

P.2: "He looks normal to me. I think he's cured...If he does have it, I would want to know how he looked that way. Are they the same medications I'm getting? I'm sure his medications cost a lot more."

P.9: "I got my diagnosis around the same time as Magic Johnson. And that helped motivate me to stay alive. I

thought he might be getting bigger too cuz of the medications. It helped me.”

P. 20: “We don’t want to feel belittled like Magic Johnson.”

P.19: “Magic Johnson is the stigma that I’m talking about. That’s the fear of everybody. People were fearing to touch him. They said “we don’t want to play with you.” That’s the same thing. That’s why there’s none of us talking about it. We don’t want people to act with prejudice against us, fearing that we will contaminate them if we touch them.”

Interpretations of REHMHA’s bodies

P.18: “I hear the word AIDS a lot in my business...”That guy doesn’t work hard, look at his body, he must have AIDS” or “Don’t touch that one, he looks like he has AIDS.” They don’t know the difference between HIV and AIDS. They say such stupid shit...and that’s all you need is the rumor mill. You can’t have that stick to you cuz then you’ll get no work. They’ll be black balling you from work because they will think that you’re contagious and that your body is no good anyway...I stay as far away from those conversations as possible...I try to make it so they don’t see me making any noise as much as possible. Sometimes that means just going along with it by not saying anything or laughing so I don’t stand out.”

P.1: “The general perception is that we are drug addicts or worthless bums really. And we have our body image

hang-ups. People have their preconceived notions based on severe lack of information and want verification about the way they feel based on severe lack of knowledge about this virus.”

P.11: “...You know sometimes it happens to me sometimes, people talk about us without them knowing that I have it, so I know what they have to say, you know, so usually most of the time it’s negative comments like we’re ugly, dying, lazy, dirty. I just listen.”

The visibility of HIV positive or AIDS defined gay men

P.5: “Everyone knows that the gay positive men are the hardest workers. They are off the hook. They work better than us. They are out there fighting the cause. We don’t do nothing. They have a fighting spirit, energy, strong, and can take care of themselves. And you got to be able to throw down to beat one of them guys. I ain’t never seen one that couldn’t take care of themselves.”

P.1: “They are at every AIDS walk and have been since I was diagnosed in ’84.”

P.12: “___[names of individuals he states are openly gay and HIV positive] pass out condoms in my neighborhood I admire that.”

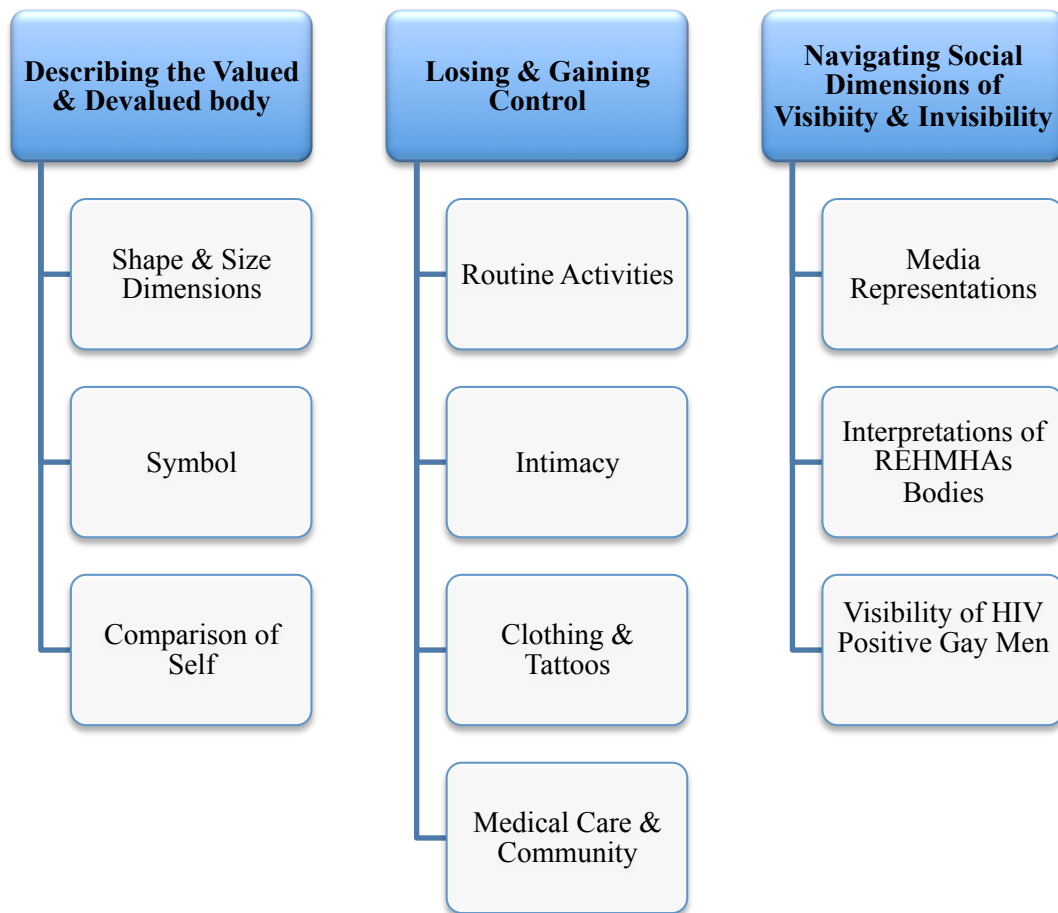
P.20: “The first men that I met in ___[name of 12-step recovery program] were out about it [HIV positive status] were gay...They told their stories in the rooms when I would just sit there, know

my secret and say nothing.”

P.18: “They are the only people that I’ve seen that come to ___ [name of hospital clinic] and don’t hide. It’s respected.”

P.6: ___ [name of a medical professional working with participant] is gay and talks about his diagnosis with me. That is the first man that I’d seen do that. He tested me when I was diagnosed...Got me medications when I thought I’d die.”

Figure 1. Diagram of super-ordinate themes and sub-categories of REHMHA body image.



Appendix 1

Research Recruitment Flyer

HIV Positive Male Body Image Study

- Are you a male identifying as heterosexual/straight and as a racial/ethnic minority (e.g., Black, Latino, Hispanic, African Native, American Indian), diagnosed with HIV, and a patient in care with ____ [name of hospital site]?
- Have you taken HIV medications for at least 6 months?

If you answered YES to these questions, you may be eligible to participate in a body image research study.

The purpose of this study is to gain a firsthand understanding of how men identifying as heterosexual and racial/ethnic minorities living with HIV and using or having used Highly Active Antiretroviral Therapy (HAART) understand their body image.

Men diagnosed with HIV, identifying as heterosexual, racial/ethnic minorities, 18 years of age or older, and in active care with ____ [name of hospital site] are eligible to participate.

This study is being conducted by ____ [name of hospital site with address].

Please call Michele Vella at ____ [phone number] for more information

Semi-Structured Body Image Interview Guide

Explanation of what will be discussed within the semi-structured interview:

In this individual interview, I would like to explore the way you may have experienced your body before becoming HIV positive and then after being diagnosed with HIV and taking Highly Active Antiretroviral Therapy, the combination of medications that you may use or have used to treat HIV. You may call these medications HAART or you may call them your HIV medications/meds. The attitudes, feelings, beliefs, and even the way you think about your body's shape and size may all be part of what is called body image. For this study, I am defining body image as being made up of three ingredients. (1.) The first ingredient is your own perceptions about your shape and size. (2.) The second ingredient is about your behaviors or changing the things that you do or have done because of the negative or positive feelings that you have or had about your body. (3.) Finally, the third ingredient is what you believe society thinks about the bodies of men (and in some instances women) living with HIV or AIDS.

I. The Perceptual Domain (Information related to shape and size):

- Tell me about what you believe would be the perfect shape and size for a man's body?
Probing Question:
 - Imagine we are looking at a magazine or video and that you could point out that perfect shape and size. Could you describe it to me?

- In your opinion, are there parts of your body that you think should be a certain shape or size?
Probes
 - The chest
 - The arms
 - The legs
 - The waist
 - The stomach

- Could you describe a time in your life when you thought that your body shape and size was at its best or on point?
Probing Question:
 - This doesn't have to be in the past, it could even be now.
 - If we were flipping through a photo album and you found a picture of yourself at your best, what would your body's shape and size look like in that picture?

- How would you describe the shape and size of your body before becoming HIV positive?

Probes:

- Your height
- Your neck
- Your legs
- Your arms
- Your stomach/chest
- Your waist

- How would you describe the shape and size of your body after becoming HIV positive and before you started taking your HIV medications? (Use of this question may vary depending upon when the participant started taking medications. For example, was it right when they got diagnosed or did they wait to take medications because of denial; they simply were not ready to adhere to medications, or a doctor may have encouraged them to wait for several months before starting the medications).
- Did you notice anything different about your body's shape and size after becoming HIV positive and taking your HIV medications?

Probing questions/scenario:

- Sometimes men will look at a picture of themselves after being diagnosed with HIV and taking their HIV meds and notice some differences in their shape and size. Did you ever have that happen to you?
- Take me back and talk about what the shape and size of your body looked like to you at that point.

If the participant reports changes in shape and size

- Did anybody ever comment to you about the changes in your body's shape and size after becoming HIV positive and taking HIV medications?

Probes

- Your doctor
- Family members
- Friends
- A partner
- Strangers

II. The Behavioral Domain (Changing the things that you do or have done because of negative or positive feelings about your body):

Feelings

- What feelings did you have about your body before becoming positive?
- What feelings did you have about your body after becoming positive?

- What feelings did you have about your body after becoming positive and taking HIV medications?
- Is there a difference in your feelings about your body before and after your diagnosis?
- If you can remember, have your feelings about your body changed over time?
- Does anything trigger positive or negative feelings that you have or had about your body?
- Do you feel that you can talk about the way you feel to anyone else? If so, who?
 - Friend, family member, church group, pastor, counselor, doctor, other HIV positive peer, clinic staff (clients tend to share a lot with certain members of clinic staff)
- Is there anything that has been a source of strength, encouragement, resilience, or support as you've faced the changes you've mentioned?

Behaviors

- As a man, are there things that you will or will not do in your day because of any negative or positive feelings you have about your body?

Probes

- Looking in the mirror/or not looking in the mirror
 - Eating more/less
 - Getting on a scale at the doctor's office/getting weighed
 - Avoiding going to a doctor's appointment
 - Skipping medications
 - Exercising, going to the gym, lifting weights
 - Talking to friends about your body
 - Buying magazines
 - Taking supplements
 - Steroids
 - Wanting to be touched more or less
 - Thinking about plastic surgery
 - Wanting more or less attention
 - Drug use (increase or decrease if there is a history or current drug use)
 - Sexual activity, sexual risk taking
 - Wearing different clothes to hide or enhance certain parts of the body
- You are going the pool/ water park/ beach **before** being diagnosed with HIV. As a man, what would you wear or not wear?

- As a man, is what you feel comfortable wearing influenced by other factors such as your age, having children, your family, what your community or friends would find acceptable/not acceptable for a man?
- You are going to the pool/ water park/ beach **after** being diagnosed with HIV and taking your HIV meds. As a man, what would you wear or not wear?
 - Probing question to examine for other influences:*
 - As a man, is what you feel comfortable wearing influenced by other factors such as your age, having children, your family, what your community or friends would find acceptable/not acceptable for a man?
- Do you notice feeling more or less intimacy with those closest to you because of the positive or negative feelings that you have about your body?
- Have you worried about how the people closest to you might handle the changes that you have experienced in your body after becoming HIV positive and taking HIV medications?

III. The Subjective Domain (The social value placed on the HIV body and the representations of this body)

- When was the last time you saw a HIV positive straight/heterosexual man in the media?
 - Probes*
 - Who was it?
 - What did he look like?
 - Where else have you seen...? (varying according to participant response)
- Can you describe a typical HIV positive White man that you see in the media (media may be magazines, television shows, movies, etc.)? Can you describe a typical HIV positive African American (example) that you see in the media? Do you see any differences between the two images?
- Let's imagine you were talking to a man in your neighborhood and he didn't know you were HIV positive. What do you think he would tell you about what a man diagnosed with HIV looks like?
 - Do you think he would talk about the looks of a HIV positive African American (example) straight man in the same way he would talk about the looks of a HIV positive African American (example) gay man?
- Have your ideas about what men diagnosed with HIV look like changed from before and then after you became positive? If so, how?
 - Before taking your HIV meds and then after taking your HIV meds?

- Let's pretend you are the interviewer for this study, instead of me. Magic Johnson walks in the room and wants to participate.
 - Probing Questions*
 - What would you ask him about the way he looks?
 - What would you ask him about his HIV?
 - What would you ask him about being a HIV positive straight African American man?
- Do you think that people in general think straight men diagnosed with HIV...
 - Probes*
 - Work?
 - Are hard workers?
 - Are strong?
- Do you think people in general think straight Puerto Rican men (example) diagnosed with HIV
 - Work?
 - Are hard workers?
 - Are strong?
- Do you think people in general think gay Puerto Rican men (example) diagnosed with HIV
 - Work?
 - Are hard workers?
 - Are strong?
- Could you tell me if you have ever heard these words said about a HIV positive straight man? If so what have you heard?
 - AIDS carrier
 - AIDS victim
 - AIDS survivor
 - "He's got the package"
 - "He's got the monster"
 - "He's got the look"

IV. Other

- Is there anything that you would like to clarify or anything that you would like me to clarify?
- Is there anything else you would like to add?
- Should anything be taken out?
- Is there anything you feel might be helpful for me to talk about with other men who will participate in my study?

Appendix 3

Demographic Questionnaire

Please check off the box or fill in a response to the questions below

- a.) Do you have HIV or AIDS? HIV
 AIDS

b.) Years living with HIV or AIDS: _____

c.) Years or months taking HAART: _____

d.) Age: _____

e.) Relationship status:

- Single
 Married
 Separated
 Divorced
 Widower
 In a relationship

f.) What color best describes your skin? _____

g.) Identity

- African American
 African Native from _____ country in Africa
 American Indian from _____ tribe (if known)
 Asian or Asian American from _____ country (if known)
 Hispanic from _____ country, commonwealth, or territory (if known)
 Latino from _____ country, commonwealth, or territory (if known)
 Native Pacific or Hawaiian Islander from _____ town, city, village, territory (if known)
 Mixed identity (please indicate what your identities are): _____
 Other _____

h.) Language:

What language do you identify as your primary language? _____

What language do you identify as your secondary language? _____

i.) Education:

- | | | |
|--|---|---|
| <input type="checkbox"/> Some high school | <input type="checkbox"/> Some college | <input type="checkbox"/> Some masters study |
| <input type="checkbox"/> GED | <input type="checkbox"/> Associate degree | <input type="checkbox"/> Master's degree |
| <input type="checkbox"/> High school diploma | <input type="checkbox"/> Undergraduate degree | <input type="checkbox"/> Doctorate degree |
| <input type="checkbox"/> Vocational schooling
(for example: mechanic, plumber, carpentry) | | |

j.) Are you currently employed?

- Yes
 No

k.) Income level

- Under \$20,000
 \$20,000 -\$39,999
 \$40,000-\$59,999
 \$60,000-\$79,999
 \$80,000-\$99,999
 Above \$100,000
 Other (please write in response): _____

Appendix 4

Body Image Survey

a.) Do you exercise regularly?

Yes

No

If so, describe what exercise you do? For example, types of exercise may include walking, running, weight lifting, jumping rope swimming, boxing: _____

Approximately how long in minutes or hours per week do you do this exercise?

b.) Are you able to afford a gym membership?

Yes

No

c.) Do you feel that you eat a healthy/balanced diet?

Yes

No

d.) Do you feel as if you could eat better?

Yes

No

If you checked “yes”, what do you think you could do to improve your diet? (Please fill in a response) _____

e.) Do you have any chronic medical conditions that you were diagnosed with by your medical provider aside from HIV? For example, chronic medical conditions may include diagnoses made by your doctor such as diabetes, high blood pressure, thyroid disease, hepatitis C, depression, anxiety.

Yes

No

If you checked “yes”, please indicate what other chronic medical conditions: _____

f.) Did you have any surgical cosmetic procedure(s). For example, surgical cosmetic procedures may include liposuction, gastric bypass, lap band, nose job, face lift, peck implants, penis enhancements) before your HIV or AIDS diagnosis?

Yes

No

If you checked “yes”, please indicate what surgical cosmetic procedures you had done: _____

g.) Did you have any surgical cosmetic procedure(s) after your HIV or AIDS diagnosis? For example surgical cosmetic procedures may include, liposuction, gastric bypass, lap band, nose job, face lift, peck implants, penis enhancements.

Yes

No

If you checked “yes”, please indicate what surgical cosmetic procedures you had done: _____

h.) Would you consider getting a surgical cosmetic procedure for areas of your body that you may dislike if you insurance covered the procedure for you?

Yes

No

If you checked “yes”, please indicate what surgical cosmetic procedures you would like to have done: _____

i.) Did you ever get any facial injections to even out fat loss in your face? This may include Sculptra or Botox?

Yes

No

j.) Did you ever inject yourself with a human growth hormone like Serostim to reduce fat in your stomach?

Yes

No

k.) Did you ever inject steroids?

Yes

No

l.) Did you ever use testosterone replacement? This could come in different forms like gels, skin patches, mouth patches, injections, or implants.

Yes

No

m.) Do you take dietary supplements to enhance muscle tone such as whey protein powder, creatine powder, or protein bars?

Yes

No

n.) Do you have tattoos?

Yes

No

If you checked “yes”, how many do you have? _____

o.) Did you get most of these tattoos before or after you were diagnosed with HIV or AIDS?

Before HIV or AIDS

After HIV or AIDS

If you got them after your HIV or AIDS diagnosis, what regions of your body did you get them on?

Hands

Chest

Wrist(s)

Stomach

Neck

Upper thigh(s)

Face

Calf(ves)

Arms

Other

p.) Do you shave your hair on other areas aside from your face and neck?

Yes

No

If you checked “yes”, please place a check next to what body parts or areas you shave:

Under arms/armpit

Arms

Chest

Legs

Pubic or genital area (for example: penis, testicles, etc.)

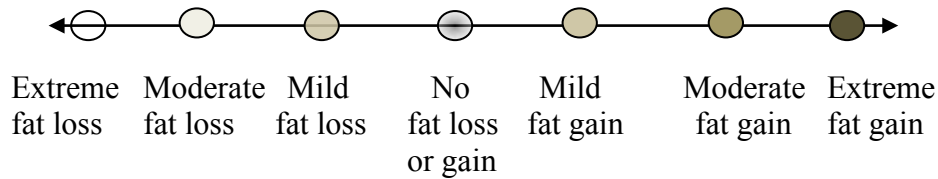
Other: _____

Appendix 5

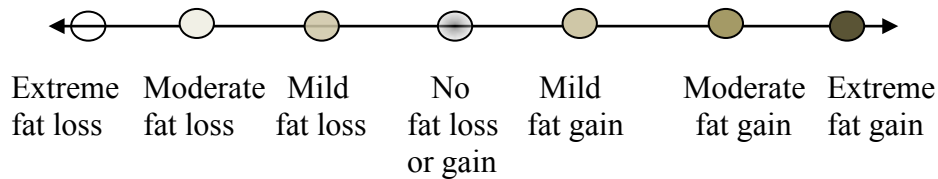
Perceived Lipodystrophy Scale (PLS)

The following questions will ask you to rate your perception of fat loss or fat gain on certain areas of your body. Please place an “x” for the response that best matches your perception of fat loss or fat gain.

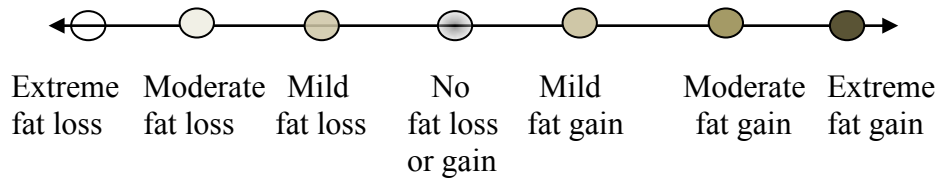
a. My face



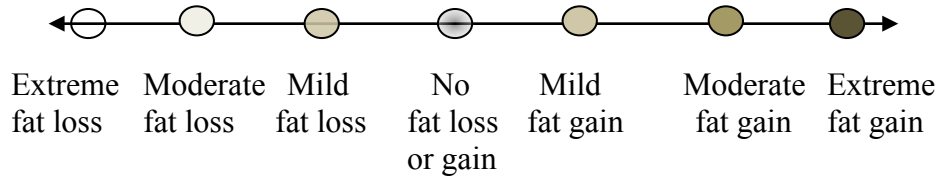
b. Under my chin



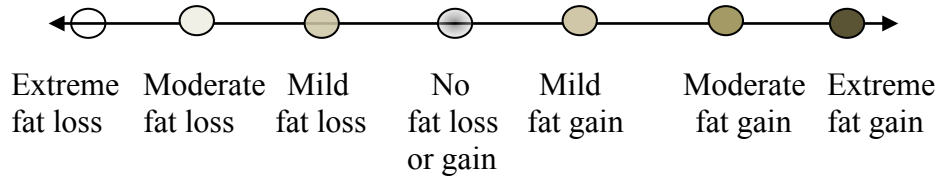
c. The back of my neck



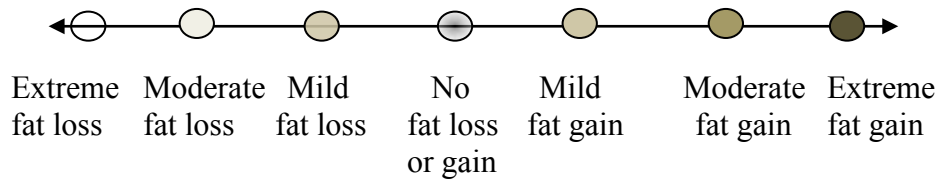
d. My upper arm



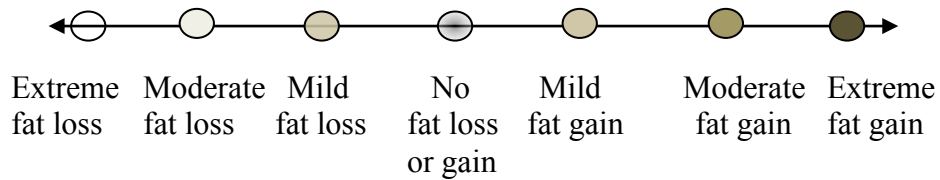
e. My lower arm



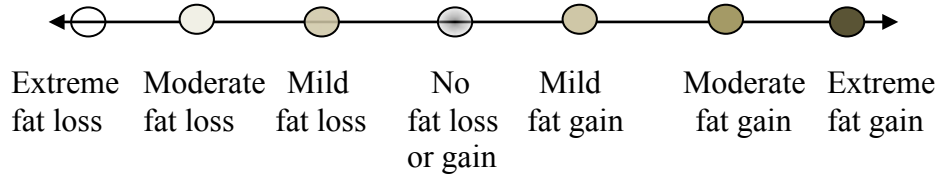
f. My abdomen or stomach



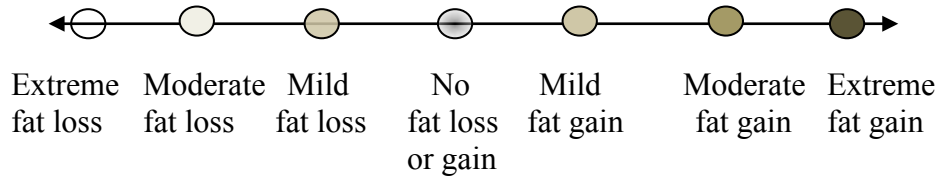
g. My chest and/or pecks



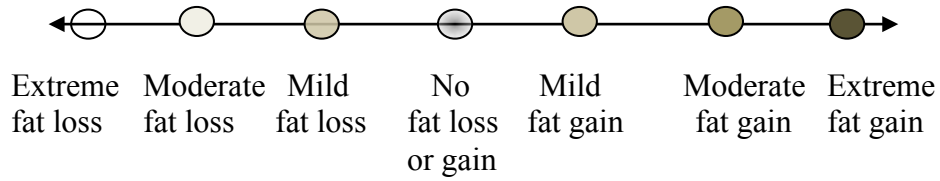
h. My upper thigh



i. My lower legs/calves



j. My butt



Total= _____

Appendix 6

Informed Consent Form

Informed Consent

Name of Researcher: Michele Vella

Name of Institutions: Lehigh University and ___[name of hospital research site]

Name of the Project: Fat, Muscles, and Medicine: Body Image Experiences of Racial/Ethnic Minority Heterosexual Males Living with HIV/AIDS

Introduction

Michele Vella is a graduate student at Lehigh University in the Counseling Psychology program. She is completing this research study as part of the fulfillment of requirements towards her Ph.D. For this study, she will be supervised by her Lehigh University academic advisor, Dr. Grace I. L. Caskie. She will also be supervised at ___[name of the hospital site]. This document will give you information to invite you to be part of the research study. If you have any additional questions about the study, please feel free to ask the investigator at any point.

Purpose

Men living with HIV/AIDS may have different side effects on their bodies as a result of taking Highly Active Antiretroviral Therapy (also known as HAART). The majority of research studies on HIV/AIDS, HAART, and body image were conducted on males identifying as gay or men who have sex with men (MSM). For this study, the researcher will be asking you to report on your body image since becoming HIV positive and taking HAART now or in the past. The researcher will ask you a series of questions about your body image as a male identifying as HIV positive or AIDS defining and heterosexual. She will define body image according to a starting framework to help you speak about your body image. Your experience of body image may include but is not limited to three ingredients:

- a.) your own (internal) and society's (external) perceptions about your body's shape and size,
- b.) changing the things that you do because of negative feelings that you have about your body or feeling anxiety, depression, or stress because of dissatisfaction with the way your body looks,
- c.) the social value or its usefulness or uselessness you feel may be placed on your body because of the changes it has undergone since becoming HIV positive and taking HAART.

From your responses, the investigator will generate a research paper with the purpose of exploring body image issues specific to heterosexual males living with HIV/AIDS and taking HAART to inform both clients like yourself and their providers (e.g., medical doctors, case workers, therapists).

Type of Research

This research will involve your completion of three surveys and participation in one interview, in an individual format with the researcher asking you to speak about your experiences or opinions on a series of questions. Completing the two surveys and participating in the one interview should take 90-120 minutes or an hour and a half to two hours.

Participation

You are being invited to participate in this research because the researcher feels that your experience as a heterosexual man living with HIV/AIDS and taking HAART can contribute to helping clinicians and other helping professionals provide more support for heterosexual men living with HIV and having body image concerns.

You will be given a \$50 Visa gift-card as compensation for your participation time in this study. This \$50 Visa gift-card will be distributed to you when you arrive for the interview portion of this study.

Procedures

You will be asked to fill out three surveys before starting the interview portion of the study. The first survey will ask you basic information about yourself, the second survey will ask you information about your body, and the third survey will ask you about fat increases or decreases in different parts of your body (you will NOT be asked to give your real name on the surveys). The second portion of the study will ask you to take part in a discussion about body image with the researcher. You will be asked to respond/comment on a series of questions on body image (as defined above). Michele Vella will serve as the question facilitator or moderator of your interview. The discussion will take place at ___[name of hospital site] in room #8. The entire session will be audio-recorded, and you will be able to see the recorder at all times. The audio-recording will then be transcribed. Your name will not be used on the transcription, and if you have any personal identifying information that you use in the context of our discussion, it will be deleted on the transcript. The audio-recording will be erased or destroyed after this transcription occurs. This will take no more than one week from the time of your interview.

Duration

As mentioned above, your participation will take a total of 120 minutes (30 minutes for you to fill out the two surveys plus approximately 60-90 minutes to complete the interview for a potential total of 120 minutes). This will take only one trip/visit to the hospital where the research will be conducted.

Risks

You may experience some fatigue when completing the surveys. You may also feel some psychological distress as you reflect on your body image experiences. At any time during your participation in this study, you are free to leave without loss of gift-card benefit. You may also receive counseling services through a referral to ___[name of hospital site] or a community counseling mental health clinic if you feel that you need counseling. This referral could be facilitated directly through ___[name of behavioral health specialist at hospital site with contact information] or through your case manager.

Benefits

You may feel supported and validated from speaking or reflecting on your own body image body image experiences. You may become more engaged and empowered in your own medical care through assisting in this study.

Confidentiality

You will not be asked to identify yourself by your real name at any point in this study. Instead, you will be assigned a study number on your survey documents. If you reveal any identifying information within your individual interviews, this will NOT be included in the audio transcription. As mentioned above, the audio recording will be deleted from the audio recorder within one week of your interview. The audio recorder will be kept in a locked file cabinet and behind a locked door. The final transcription, without any of your identifying information will be kept in a password protected computer that only the researcher and her academic advisor, Dr. Grace I.L. Caskie will have access to.

Right to Refuse or Withdraw

You do not have to participate in this research if you do not wish to do so. You may stop participating in this research at any time that you wish to (for example, during the survey portion or during the interview portion) without affecting your medical care.

Contact Information and Telephone Numbers

If you would like to discuss or address problems, discuss your rights as a research participant, address concerns, questions, information or input with someone independent of the research or if you have any complaints about the research you may contact.

Research Participation Protection Office

If you have any questions, concerns or complaints about this research study or experience a study related injury during your participation in this study, please contact:

_____[Name, address, and phone number of IRB at hospital site]

Michele Vella or Dr. Grace I. L. Caskie

Lehigh University, Counseling Psychology

111 Research Drive

Bethlehem, PA 18015

-Contact Information for Michele Vella

Phone number (610) 417-8727 or email: mmv207@lehigh.edu

-Contact Information for Dr. Grace I.L. Caskie

Phone number (610) 758-6094 or email: caskie@lehigh.edu

If you have any questions or concerns regarding this study and would like to talk to someone other than the researchers listed above, **you are encouraged** to contact Susan E. Disidore at (610) 758-3020 or Troy Boni at (610) 758-2985 (inors@lehigh.edu) of Lehigh University's Office of Research and Sponsored Programs. All reports or correspondence will be kept confidential.

This proposal has been reviewed and approved by the Lehigh University and ____[name of hospital site] Institutional Review Boards whose tasks are to make sure that research participants are protected from harm.

I have read the above information. I have had the opportunity to ask questions about it and any questions that I did ask have been answered to my satisfaction. I consent voluntarily to participate in this study. I also consent to be audio recorded for this study.

Print Name of Participant _____

Signature of Participant _____

Date _____

I confirm that the participant was given an opportunity to ask questions about the study and all the questions asked by the participant have been answered correctly and to the best of my ability. I confirm that the individual has not been coerced into giving consent and the consent has been given freely and voluntarily.

A copy of this signed Informed Consent Form has been provided to the participant.

Print Name of Researcher _____

Signature of Researcher _____

Date _____

Biography

Michele M. Vella, M.S., M.A., M.Ed. is a doctoral candidate in Counseling Psychology at Lehigh University. She was an American Psychological Association Mental Health and Substance Abuse Services Policy Fellow (2011-2014) and completed her pre-doctoral internship in Clinical Psychology at Mount Sinai St. Luke's and Roosevelt Hospitals, Department of Psychiatry and Behavioral Health. Next year, she will be a Postdoctoral Fellow in Clinical Psychology with an Emphasis in Clinical Health and Interprofessional Training in Primary Care at the Department of Veterans Affairs, Manhattan Campus.