

BODY IMAGE AND HIV: EXPLORING THE STORIES OF HIV-POSITIVE WOMEN

BODY IMAGE AND HIV: EXPLORING THE STORIES OF HIV-POSITIVE WOMEN

By

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Abstract

This study explored the relationship that HIV-positive women have constructed with their bodies both pre-HIV and post-HIV diagnosis. The research was based on feminist and postmodernist theoretical perspectives and narrative based qualitative interviews with six HIV-positive women residing in Ontario. The women's narratives formed the basis of the data analysis. The findings revealed stories of women's complex relationships with their bodies that were influenced by cultural discourse of the female body, change to their bodies post-HIV, side effects of HIV medications, a yearning to change their bodies with cosmetic procedures, and HIV-related stigma. While women's stories illustrated reflections from the past and present, their stories also moved non-linearly through time. These stories challenged the idea of a grand truth about how women experience their bodies and suggested women's relationship with their bodies is an active and fluid process. The theoretical perspectives of this research and the stories of HIV-positive women provided implications for future social work practice and research. Feminist and postmodern approaches are encouraged in future research and practice to promote non-silencing and non-pathologizing experiences for HIV-positive women. The stories shared by women suggested that the dominant model of female beauty affects the relationship constructed with their bodies and shapes the lives of women both pre-HIV and post-HIV diagnosis. These stories validated that body image concerns are indeed present in women living with HIV, just as they are present for HIV-negative women.

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Chapter One:

Introduction and Literature Review

Introduction

The purpose of this thesis is to explore how HIV-positive women experience their bodies today as well as exploring how women experienced their bodies pre-HIV diagnosis. While I am not HIV-positive my personal experience as a woman, who attempted to manage cultural messages directed at my female body, influenced my passion for this area of study and this thesis. Women live within a culture that seeks to influence and control their bodies through social and cultural messages that encourage adherence to a female beauty ideal. The navigation through such messages can create a complicated relationship with the female body. While female body image has been a popular focus in research, this research is unique through the recognition that there are women who may experience an even more complicated relationship with their bodies due to biological, psychological and social barriers such as the presence of a disability resulting from HIV diagnosis. While all women experience the socio-cultural landscape that seeks to influence their bodies and the relationship they form with their bodies, women living with HIV experience an intersection of social and cultural discourse of the female body with the experience of HIV-related physical changes to their bodies, medical control of their bodies, and HIV-related stigma.

The theoretical backbone of the research is in feminist and postmodernist theory with narrative based qualitative interviews. Through this research I hope to challenge dominant discourses that stigmatize the HIV-positive body by highlighting the intersection of HIV-related stigma, discrimination, and sexism as it relates to body image. In challenging dominant discourses, I hope to challenge the dominant model of feminine beauty while also challenging traditional approaches to research and practice as it relates to both body image and HIV. The women's stories highlighted the relationships these women constructed with their bodies pre-HIV, the relationship constructed with their bodies post-HIV, and a fluid story about the relationship women construct with their bodies over time. What follows is a story of my research process, findings and reflections. Overall the stories shared illustrated that HIV-positive women experience body image concerns like HIV-negative women, but also experienced HIV-related physical change, stigma, and stress that created a complex relationship with their bodies.

Literature Review

To begin the research process I reflected on what makes body image concerns among women living with HIV unique. In coming to focus on body image among women living with HIV it remained unknown what information was available within existing literature. Frustration emerged when confronting the literature on the female-bodied experience as much of the research did not focus on marginalized women. When I was encouraged to look beyond the norm and privileged position of much body image literature I was able to

approach body image from a feminist position and include the marginalized experience that is associated with HIV-positive status.

The following review explores the present literature on women living with HIV, and on women's experience with body image. By focusing on the issue of attention (body image) and the population of focus (women living with HIV), the literature review encouraged me to explore questions and themes that have traditionally been excluded from research and that require a far more in depth focus in the research process. The literature review explored body image as it relates to all women, then information on women living with HIV, their experience with body image, and their experiences with HIV-related medication and stigma.

Body Image Among Women

The topic of body image among females saturates literature in disciplines from psychology and psychiatry to social work and sociology. The concept of body image itself is not unique and is not of focus to this research rather, it is the intersectionality of HIV and body image that is unique and is of interest here. The review of the literature illustrated a dominant discourse of body image as it related generally to a number of themes including women's experience with their bodies and the social and cultural forces that shape the construction of the female body. There are two competing perspectives that are present in the literature on women and body image, the traditional approach and the

feminist approach. Traditionally literature and theories have constructed a medical view of body image as a mental health concern from which the individual is the focus of treatment. Literature on body image showed a contrast between theoretical perspectives that pathologize and individualize the concern of body image and theoretical perspectives that identify body image as a fluid concept that is the result of socio-cultural discourse. The feminist lens I draw upon is encouraged by the idea of a larger system of power influencing images aimed at women and beauty that are meant to shape women's lives. The summary of literature is intended to draw upon knowledge of others to both present body image as a relevant concern, but also as a feminist interest that shapes women's development and health. While I approached body image as a fluid process in one's life, the literature review included articles that conceptualized body image as a rigid construct in order to provide a full picture of the research to date

Messages from socialization within Western culture suggest an ideal female encompasses a thin body and features deemed beautiful by cultural forces, and that this body will lead to success and health (Hesse-Biber, 2004). A powerful metaphor used in literature referring to cultural messages aimed at women is the "cultural mirror" as a "measuring stick" of a woman's bodied value (Hesse-Biber et al., 2004, p. 210). The ideal female body is created and sustained by cultural messages that are then internalized by women as a tool of measurement of beauty. The pernicious influence of the culturally designed model of female beauty is pervasive; Silberstein et al. (1986) wrote body image dissatisfaction among women is so prevalent that it can be considered a normal

experience in female development. Negative body image is most often characterized by low self-esteem and body dissatisfaction, occurring when socio-cultural messages teach women their body is flawed resulting in a need to adjust the body (Leon et al., 1993; Stice, 1994; Peterson et al., 2006; Hartley, 2010). Literature further suggested negative body image could lead to tensions between the actual physical form and the psychological wishes for a different body. Young (2005) described the tension between the ideal female body and the reality of women's bodies by writing "it is an ideal only few women's bodies approximate, but given power by the media the norm is ubiquitous, and most women internalize it to some degree making self-abnegation inevitable" (p.79).

The traditional view of body image is considered a medical view including diagnostic criterion, symptomology, and treatment plans. Negative body image is medicalized as body dysmorphic disorder (BDD) according to the DSM-IV (American Psychological Association, 1994). BDD is "classified as a somatoform disorder and involves a preoccupation with imagined or slight defects in physical appearance" (American Psychological Association, 1994), which leads to "significant distress and/or social or occupational impairment" (Wilhelm, 2010, p.241). Despite the prevalence of BDD being represented by less than 2.4% of the general population, it is listed as more common than schizophrenia and anorexia (APA as cited in Didie, 2010). Greenberg (2010) wrote, "body image concerns are common and are of personal and public health significance" (p.237). The statistics suggest poor body image is experienced by half of all women (Cash & Henry, 1995), and that 75% of women over the age of 18 believe they are overweight

(Hartley, 2010). For this reason much of the literature spoke of best practices to treat body image dissatisfaction. The UK based National Institute for Health and Clinical Excellence (2004a, 2004b) described cognitive behavioural therapy as the best practice addressing body image concerns. This therapy posits negative body image develops because of an individual's problematic thought patterns. The traditional lens focuses on negative body image as problematic for mental health reasons and treatment as a dominant discourse. What is excluded is a deconstruction of the larger narrative that creates and supports negative relationships between women and their body.

Approached differently than traditional theories of body image, feminist theorists have spoken extensively to the issue of body image as a structural representation of female oppression. Brown (1985) wrote the cultural ideal of the female body is a "manifestation of misogynist norms flowing from a culture where women are devalued and disempowered" (in Hartley, 2010, p.247). Further, Davis (1997) wrote the "female body represents discourse of power that justify social inequality and power inequality based on gender" (p.10). This echoes in the work of Young (2005), who wrote "despite much change in society, the image of women is still that of the vulnerable other" (p.3). The vulnerable other position of women is the position inhabited by the thin woman or the women consumed with attaining this position. Numerous authors have suggested the time and economic consumption involved in attaining the female body ideal distracts women from creating space to express political interests, empowerment, and resistance against the oppressive discourses that relate to women (Brown & Jasper, 1993; Attie & Brooks-

Gunn, 1987, Hesse-Biber, 1996; Hesse-Biber et al. 2004). From a postmodern perspective, the Foucauldian concept of “docile bodies” (1979, p.28) can be used to describe power at the micro and macro level that is directed to discipline the female body. Wolf (1992) wrote the feminine strive for thinness is more about obedience than beauty. The discipline involved in the creation of the docile body encompasses a lifestyle of management involving monitoring and governing the body’s hungers and reducing the size of the body to limit the space that is taken up by the female form. These are practices that are a part of the “tyranny of slenderness” (Bartky, 2010, p.87). Self-esteem and self worth are intrinsically tied to women’s abilities to manage and control their appearance, thus the greater obedience to the model of the female body should yield a more positive bodied experience (Brown et al., 2008). Literature on body image among women focuses on the individual’s strive for beauty as influenced by socio-cultural norms and suggests this can be attributed to the experiences of most women throughout development. The feminist lens allows movement away from the traditional medical view, and an opportunity to deconstruct the powerful discourse that infiltrates the relationship women form with their body.

Women and HIV

Women living with HIV are largely missing from HIV-related research. Although rates of HIV in women are increasing, the experiences of women living with HIV continue to be under-researched (Gurevich et al., 2007). Internationally, there are 17.6 million women living with HIV or 47.3% of HIV-positive adults in the world (Shah & Bradbeer, 2000).

The proportion of women receiving HIV-positive diagnosis has more than doubled in the last twenty years, from 12% in 1985 to 1997, to 25.4% in 2002 (Health Canada, 2003). Young women particularly are at high risk for infecting HIV. HIV diagnosis for women are highest among young adults, in 2001 44.4% of new diagnosis of young adults were women (Health Canada, 2003). Further, women of certain ethnicities have increased representation in the HIV-positive community. Aboriginal women and Black women are 3 times more likely than White women to be diagnosed with HIV (Health Canada, 2002a, Health Canada, 2002b). Women living with HIV experience intersecting barriers such as psychological stressors, racism, poverty, nutrition, abuse and parenting responsibilities (Gallego, 1998; Tangenberg, 2000; HRSA, 1998; Wood, 2007; Greene et al., 2010). Another barrier is a financial one; a 1998 survey found 74% of respondents living with HIV had an income under \$29000 and half of HIV-positive respondents stated their financial circumstance changed for the worse since the time of their diagnosis (Canadian Aids Society, 2004). Women living with HIV therefore are more likely to experience significant barriers associated with age, race, and poverty. A dangerous process is occurring for which women living with HIV are at great risk while receiving little attention from research and the benefits that come from it.

HIV, Women and Body Image

Exploration of body image and HIV is considered through a traditional lens by three studies, which portrayed a narrative of change to the body and a dislike for the changes to

the body post-HIV diagnosis. Corless et al. (2004) conducted a study focused on the correlation between HIV-related weight change and body image. A relationship was found between greater weight and better quality of life for HIV-positive individuals (p.295). Martinez et al. (2005) studied body image perceptions of women living with HIV. Results of the study suggested HIV-positive status is “related to poorer body image” (p.155). Lastly, Sharma et al. (2006) studied the association between HIV-positive status and negative body image among women. The authors found that although women living with HIV are less likely to be overweight, women living with HIV are less satisfied with their bodies than women who are not HIV-positive. Overall, the research studies found a relationship between HIV-positive status and negative body image that was not explicitly related to weight.

Controlled Bodies

A second distinguishing feature of body image among women living with HIV is the medical control of the body. In the review of literature on the medical forces present in the daily life of people living with HIV, Foucault’s (1979) notion of bio-power emerged. Bio-power is used by multiple texts to describe the biomedical discourse which influences and has power over the HIV-positive body and is described as disciplining and controlling the body through micro and macro level influences (Persson et al., 2003; Caldwell, 2007; Keenan, 2001; Sawicki, 1991; Tangenberg & Kemp, 2002). At the macro level, HIV is governed by a focus of risk management (Galvin, 2002), that is used to

eliminate or control problematic behaviours that are deemed deviant such as unprotected sex, non disclosure to others, and risky drug use (Reissman, 2010, p.51). Bio-power also operates at the micro level through self-management used to reduce the use of health services and is representative of larger managerial structuring in medical discourse (Wilson, 2001).

Self-management and medicalization emerge among women living with HIV through prescribed medications called Highly Active Anti-Retroviral Therapy (HAART). Although HAART has the ability to reduce HIV to undetectable levels and has led to decreased mortalities associated with AIDS, HAART also carries with it severe side effects (Volberdin, 2003; Wynn, et al., 2004; Persson, 2005). HAART requires a rigid schedule of ingesting pills with appropriate dietary sources, which often shapes the lives of people living with HIV (Sigel & Lekas, 2002). Along with a lifestyle that calls for rigid scheduling and diet, invasive side effects of the medication are present. Side effects of medication include: chronic diarrhea, nausea, vomiting, stomach cramps, fat loss (lipoatrophy), fat redistribution (lipodystrophy), insomnia, fatigue, depression, memory problems, sexual dysfunction, diabetes, rashes, hypertension, heart disease, liver damage, nerve damage, pancreatitis, and bone diseases (Carr and Cooper, 2000; Machon & Batrouney, 1999 in Persson, 2004). While contemplating the magnitude of the list of side effects, it is not difficult to conceive that such side effects can be lethal and disabling (Rosengarten, 2004). For medical practitioners and social workers, side effects must be taken into consideration when engaging in conversations about medical adherence with

persons living with HIV; in the past non-adherence to medication has been linked to the inability to tolerate side effects, fear of side effects and fears of disclosure (Basetti, et al., 1999). The extensive medicalization of HIV and the invasive side effects of medication are a distinct experience for women living with HIV and influence unique relationships with their bodies that are not found within HIV-negative women. For those living with HIV medication is much more than about health, it is also about control of the body.

A distinctive side effect of HAART medications on women's bodies is lipodystrophy, lipoatrophy, and other physical changes to the body. With recent advances in HIV therapies fat distribution alterations, lipodystrophy, and weight gain and loss occur as part of a broad spectrum of body alterations (Grinspoon, et al., 2003; Ridolfo et al., 2000 in Corless et al., 2004). Carr et al. (1998, 1999) and Carr (2003) described the features of lipodystrophy as: distended belly, enlarged breasts, mound of fat lodged in the back of the neck, flat buttocks, thin extremities, protruding veins, and sunken cheeks. Literature suggested greater compliance with HAART increased the likelihood of lipodystrophy (Persson, 2004), and claimed at least 50% of HAART recipients experienced a physical side effect (Carr et al., 1998; Gervasoni et al., 1999; Falutz & Turcot, 1999; Carr et al., 1999; Lichtenstein et al., 2001; Carr et al., 2000; Thiebaut et al., 2000; Heath et al., 2001). The decision to adhere to HAART is balanced with a risk of incurring physically signifying effects of such medication. It is of little surprise that change in appearance because of lipodystrophy is associated with low self-esteem, negative body image, and diminished quality of life (Blanch et al., 2004; Dukers et al., 2001; Schrooten et al., 2001;

Tate & George, 2001; Wagner & Rabkin, 1999; Maus, 2002; Collins et al., 2000). While most literature on body image among women focuses on reducing weight, women living with HIV experience better quality of life when weight is higher (Corless et al., 2004). Lenert et al. (2002) found two thirds of those enrolled were willing trade at least 1 year of life to avoid living with lipodystrophy, and 73% were willing to accept at least an additional 1% risk of death to avoid lipodystrophy. Lipodystrophy is a unique feature of life with HIV and speaks to the special challenges HIV-positive women must face when constructing a relationship with their bodies.

Stigma, Women and HIV

The stigmatization of HIV affects the relationship HIV-positive women construct with their bodies. Other chronic illnesses, such as cancer and rheumatoid arthritis, physically change the appearance of the body and enforce a medically controlled and managed lifestyle (Wallace et al., 2007; Li & Rew, 2010; Avery 2010). Despite some similarities in effects of illness, HIV/AIDS remains vastly unique because of the stigma attached to it. Persson (2005) wrote, “perhaps more than any other contemporary disease, HIV/AIDS has served as a powerful signifier for a range of cultural anxieties around ‘otherness’ and invasion, sexuality, and deviance, contagion and death” (p.238). Stigma was a concept theorized by Goffman (1974) and his theory of stigma is used throughout literature on HIV (Persson, 2005, Radley, 2002, Scott, 2009). Stigma is used to refer to the signs and traits that move illness from creditable to discreditable. Radley (2002) asserted HIV is

discredited by “advertisements and posters” in which “the sick and the infected are portrayed in ways that establish boundaries between (healthy) self and (sick) other” (p.2). Media representations of HIV are images of serious and debilitating illness, which further encourages fear and disdain for individuals who are HIV-positive. In Lekas et al.’s (2006) study participants stated family members had misconceptions about how HIV is transmitted, and as a result were made to experience unnecessary hygienic acts, such as using bleach to clean toilets after use, and told to refrain from touching children to adhere to their family’s inaccurate beliefs about HIV. Siegel & Lekas (2002) wrote many people living with HIV internalize the socio-cultural attitudes, which leave them feeling “tainted and devalued” (p.59). Lekas et al. (2006), found HIV-positive women believed that they were more likely to be categorized as “irresponsible” and “judged by society” than their male counterparts (p.1172-73). Experiences of HIV-related stigma were highlighted in various studies that found "women are situated inside an 'economy of blame' (Patton, 1994) as 'victims, virgins, vamps' (Gorna, 1996) and ‘vectors’" (Patton, 1994, in Gurevich et al. 2007, p.15). Women incur increased internalization as a result of the dominant discourse, which posits women living with HIV as “dirty, diseased, and undeserving” (Lawless et al., 1996 in Gurevich et al., 2007, p. 13). The internalization of stigma was evidenced in Lekas et al.’s (2006) findings that reported women living with HIV “used terms like leper, contaminated, walking disease, and a germ, to describe how they perceived themselves after experiencing hygienic degradation” (p.1188). Literature suggested the stigmatization of HIV by dominant discourse results in the internalization of the negative stereotypes and ideas of deviancy. The stigmatizing experience of being

HIV-positive is challenging and women living with HIV create a relationship with their bodies through, or despite of, this lens.

The literature had many insights for study of body image, HIV, and women. Traditional and feminist approaches suggested body image dissatisfaction is a prevalent issue for most women. Body image dissatisfaction was exacerbated with the onset of HIV, HIV-related change to the body, and HIV-related stigma. As highlighted above, women living with HIV develop a unique relationship with their bodies that is different from women who are HIV-negative. It is a feminist concern that social and cultural forces continue to shape the way women feel about their bodies and that women living with HIV feel undervalued and differently stigmatized than their male counterparts. Women living with HIV must construct a relationship with their bodies amid multiple tensions and influences that includes negative perceptions of HIV, physical changes to the body, and navigation through Western culture portraying a narrow ideal of the female body. The literature on women living with HIV suggested women are a marginalized group within the HIV community who require greater research attention and focus.

Chapter Two:

Methodology

Theoretical Framework

Understandings of epistemological and ontological beliefs are important because “what we think exists influences how we see” (Mason, 1997, p.104). I have come to understand knowledge creation from a social constructivist epistemology, through the belief that social and cultural forces create and maintain knowledge. I agree with Baumgartner (2007) who wrote “the self develops through interaction with others in society” (p.919). Knowledge of what it means to be a woman and what a woman ought to look like, I propose, is shaped and maintained by cultural and social forces. Two ontological beliefs I espouse, in research and practice, are that women are marginalized by present social and cultural structures, and that there is no truth that can be measured; rather each individual brings unique perspectives and truths that are equally valid. Two theories, feminism and postmodernism, are utilized in the research process.

Feminist Theory

Feminist theory involves a commitment to social change and active resistance by challenging the oppression of women through the mantra of ‘personal is political’ (Maynard, 1994; Bhopal, 2010; Letherby, 2003; Campbell & Wasco, 2000). Letherby

(2003) described the aims of feminist research as “reflexive attention to gender as an aspect of all social life, a challenge to the norm of ‘objectivity’... and develop non-exploitative relationship with research participants” (p.73). Olesen (2005) identified three elements of feminist qualitative research as: “research that problematizes women’s issues within a framework of social and historical structures; research that focuses on social justice for women; and research that creates knowledge of marginalization of women” (p.236). Overall, feminist research aims to “critique the hierarchal, deductive approach to knowledge building often found in conventional models of research” (Hesse-Biber, 2007, p.144). Because of this, feminist research utilizes qualitative methodology and focuses on the role of power in the research process. In feminist research, “the researcher appears as a living, breathing human being with concrete specific desires and interests” (Harding, 1987, p.9) rather than an “objective authority figure (Mason, 1997, p.24).

Feminist research and epistemology aligned with the research question and my own beliefs in two ways. First, feminist theory allowed the exploration of the relationship women have with their bodies as a women’s issue that is both personal and political. I understood that negative body image is much more than an individual concern; it is a gendered concern. Identifying body image as more than an individual concern allowed the space to challenge the patriarchal structure that attempts to control women through the discourse of beauty. Second, feminist theory emphasized social justice based research and empowering silenced voices. I understood that women are marginalized by a dominant discourse that seeks to create women who are docile and concerned with appearance.

HIV-positive women are further stigmatized by dominant discourses that label their bodies as ill and experience an intersection of oppressions via gender, race, health, and disability. I was able to use feminist theory to engage in research that created space for marginalized women and created knowledge about marginalized experiences.

Postmodernist Theory

Postmodernism provided a second set of values that proposed anti-oppressive and critical approaches to social work research and provided space for valuing alternative forms of knowledge such as emotion, imagination and experience (Neuman, 1997, p.82). Causality is questioned in research, as postmodern theory suggests concepts, experiences, knowledge, and identities “can be characterized as changing and fluctuating according to the context of feelings, content and ideas expressed” (Weiner-Levy, 2009, p.734). There is no grand truth to be achieved in research (Letherby, 2003); rather research offers new layers to the subjective realities of the research participants.

Postmodern theory was important as I viewed stories and the idea of truth as unique to each woman and viewed stories as fluid representations of the multiple positions one might hold at any given time. I also recognized women living with HIV hold different positions than I do, and to each other, and that all of these sources of knowledge are valid. HIV was an important factor in considering a postmodernist lens. In alliance with postmodern discourse, conceptualization was impossible. The experience of HIV and

body image are unique to each individual and, therefore, the experience cannot be compressed to one conceptual description. Although the medical model labels the experience of HIV as a disease, a postmodernist approach constructs HIV as a “transactional web of lived experiences, social discourses, and institutional medicine” (Persson, Race & Wakeford, 2003, p.398). This position is applied to the concept of body image as well. Body image is a fluid process that is influenced by multiple forces and the social positioning of individuals (Fallon & Ackard, 2002). In alliance with Gleeson and Frith (2006), I believe body image is more of an active process rather than a measurable illness as it is defined in dominant discourse. Because body image and HIV are viewed as fluid in their meaning, research interviews focused on anecdotes, attitudes, beliefs, feelings, and thoughts about the body in that moment of time not as a larger generalization. Body image and HIV were not measured as concrete, but were explored as a stories of individuals that were ever changing and shifting according to the world in which one lived. By using the phrase “relationship with their bodies” I hoped to move away from traditionally narrow definitions and more towards a more fluid understanding of women’s experience of their bodies.

As a feminist postmodernist woman I aspired to uphold this epistemology throughout the research process and writing of this thesis. I felt it was my responsibility, in aligning myself with feminist and postmodernist theory, to vigilantly pay tribute to the unique voices and stories of marginalized women.

Recruitment and Included Women

Six HIV-positive women aged 18 years or older were recruited for this study. In order to reach women living with HIV, I approached HIV/AIDS service organizations in London, Ontario and Hamilton, Ontario. Participating organizations agreed to post recruitment posters and distribute letters of information to interested participants (see Appendix A and Appendix B). The women who participated in this study were affiliated with the participating service organizations or received information of the study from social networks. The women were interviewed at various locations of their choosing. Locations included McMaster University, participants' homes, and the Regional HIV/AIDS Connection of London. One woman resided in Hamilton, one woman resided in Woodstock, and the remaining four women resided in London. Each woman received an honorarium for participating in the study consisting of \$25. The women's ages ranged from 30 years to 49 years and women reported they had been living with HIV for 2 to 25 years. While I hoped to receive a diverse sample that also included women from Hamilton, it was evident that the HIV/AIDS community in London was very receptive to the study as I received more interest than was required for the purpose of this study. The Regional HIV/AIDS Connection of London was especially receptive to my study and the women's outreach staff were excited that the research focused on women. The women's programming staff were so excited that they included a brief description of the study during community events. I was very excited by the interest in the study, especially the receptiveness of the community of HIV-positive women in London.

Qualitative Interviewing and Narrative Inquiry

I chose qualitative interviewing to create an open, discursive space that supported a narrative approach to data collection and analysis. I felt it was important to strive for research driven by my own theoretical and methodological positioning, and because of this, I hoped my postmodern feminist alignment was reflected through every step of the research process. I chose qualitative methods as the most appropriate form of data collection and analysis for the dissertation because of my desire to create space for dialogue and exploration. Leavy (2009) beautifully described qualitative research as “composing, orchestrating, and weaving rather than merely gathering data and writing a summary” (p.10). This statement informed the way I approached each step of the research process. I viewed the research question as an act of composition, the rich dialogue and conversations of the participants as an act of orchestrating the tone and content of the research, and the final analysis and writing as an act of weaving each rich narrative into a beautiful patchwork that allows each story to be heard while highlighting common threads.

Qualitative interviews were utilized to gain knowledge and collaborate with HIV-positive women. A form of interviewing called “active interviewing” was employed (Holstein & Gubrium, 1995, 1997). This form of interviewing posits interviews are “meaning making occasions” (p.113) in which interviewers “incite respondents’ answers, activating narrative production” (p.123). I was drawn to active interviewing as it described

interviews as more than questions; interviews are instead viewed as spaces where new meanings are created. Active interviewing allowed for exploration and collaboration, rather than rigidity. Qualitative interviewing provided a rich source of knowledge through stories and anecdotes of lived experience.

Narrative inquiry was chosen as it reflected postmodern and feminist research tenets. The practice of narrative inquiry stemmed from the belief that we need to hear the storied interpretations of life experience and events of traditionally silenced populations (Hendry, 2007). In choosing to research HIV-positive women, it was important for me to follow feminist theory that called for me to listen to the voices of women over my own. Connolly and Clandin (2006) asserted, “narrative inquiry is the study of experience as story and is a way of thinking about experience” (p.375). Stories of the women I interviewed were included in this dissertation in alignment with narrative research tenets. Narrative research focuses on “large sections of talk and interview exchanges that signal stories” of experience that emerge within interviews (Reissman, 2002, p.7-8). This is evident in each excerpt in the findings included to highlight the experience from each woman’s unique story. The purpose of narrative research is to gain insight to the multiple truths and meanings presented by research participants through life story, conversation, and personal writing (Connolly & Clandinin, 1990) which can act to “empower participants” (Elbaz, 1997, p.78). While creating space for marginalized women is a feminist tenet, narrative inquiry also aligned with postmodernism in presenting stories as an example of multiple truths and created space for the lived experience of participants.

Narrative inquiry placed the researcher at the forefront of the research process as more than just a writer; the researcher is a collaborator involved in ongoing construction of meaning with research participants (Richardson, 2000). My role was one of an outsider interacting with stories but not directing them, I merely posed questions and heard stories that were shared. The narrative researcher should question her own societal privilege in exploring the stories of others, as well as to question values and assumptions previously held (Barone, 2001; Coulter & Smith, 2009). In taking a non-traditional approach to the research-participant relationship, I was forced to confront my assumption about what role I would take in interviews. I had to truly practice feminist, postmodernism by passing the lead to the women I shared time with. Narrative inquiry led me down a path that minimized my role and maximized the role of HIV-positive women.

Collecting Stories

Throughout the data collection process, I remained aware of the need to consider how the women who participated could experience the research process. I attempted to collect the stories and voices of women through the least oppressive means possible. I did this by including steps in the recruitment and interview process that focused on providing the opportunity to withdraw, receive support, and feel connected to me as a person, not as merely a researcher. This began with initial contact; upon receiving a telephone call from an interested woman I would outline the requirements for participation. I was often engaged in personal conversations with women who were interested in hearing about the

research and my background. These conversations involved small talk, as well as very deep and personal revelations of struggle with HIV and body image. If interest sustained after our conversations, the woman and I scheduled a time and location of the interview that was convenient for the woman. Prior to the interview, the letter of information (Appendix B) was shared with the participating woman. The letter included the purpose, goals, risks, and benefits of the research project. Participating women were asked if concerns or questions were raised from the letter prior to reviewing the consent form (Appendix B). Consent was formally obtained prior to the start of the interview. The environmental spaces made available were non-clinical and included living spaces. During introductory conversations, I was open and shared information about my education and professional background as well as my interest in HIV and body image. Interviews were conducted one-to-one, following a narrative approach in which I asked two central queries: 1.) How would you describe your relationship with your body prior to receiving a HIV-positive diagnosis? 2.) How would you describe your relationship with your body after receiving a HIV-positive diagnosis? Asking few questions allowed me to spend most of my time listening to women share stories and expertise of living with HIV, body image, and other related experiences. I feel this allowed the women to lead the interview as the expert and hopefully minimized the role of me, an outsider academic, as the director of the conversation. Appropriate prompts were included to encourage examples and stories of experience and to further dialogue based on shared information, such as “can you tell me more about this”, or “what meaning did this experience have for

you”? Each interview was audio recorded and transcribed verbatim as per the permission granted by each woman involved.

Narrative Content Analysis

Reissman (2001) wrote the transcription of interviews requires unpacking, interpretation and analysis that reflect the uniqueness of the time and environment in which the story was told. To fully unpack and reflect upon stories from interviews a narrative informed content analysis was conducted. Drawing on Bal (1997) and Mason (2002), the content analysis incorporated reading the data on multiple levels. This tri-level analysis was useful because it gave voice to the fluidity of experiences and knowledge of the women by paying attention to the storied nature of interviews. Approaching analysis this way gave power to the story of the participant thus “privileging the participants positionality and subjectivity” (Reissman, 2002, p.3). I focused on the plot of stories reported by participants, the means in which they were conveyed, and gave voice to the timeline and history from which stories stemmed. In conducting narrative analysis, the final writing reflected the stories of participants, the themes that emerged from multiple stories, and the personal reflections on the way stories were described through the language used. Throughout this process, I was reflexive in critically assessing how questions were asked and how this influenced responses. In allowing themes to flow from stories, I wished to avoid applying pre-determined categories. The definitive goal of analysis was to explore

the experience of individual women living with HIV while also highlighting emerging themes and concepts that were a compilation of many women's unique stories.

Reflexivity

Reflexivity of one's own background and awareness of social location is of utmost importance to feminist and postmodernist beliefs (Robson, 2002). The importance of reflexive practice encouraged many hours of thought and analysis of my own social position as it related to the research process and my research interest. The social position that I hold is one of privilege compared to many living in Canada. I identify as a white woman, from a middle class background. My gender opens a door from which other women may share information with because of this commonality, but my life experience does not include living with HIV. I have never been diagnosed with a serious or long-term illness and have had no significant experience with illness in my own life or family experience. Therefore, my position as a white, middle class, non-HIV-positive, woman was present throughout this study and should be highlighted. My social position may have impacted responses and also recruitment.

Body image is a different story. As a young woman, I struggled with my appearance. I remember many experiences in which I obsessed over images from media to imagine how I could attain an ideal body. I still struggle each day to balance the tension between how I ought to look according to cultural norms and how I appear. Although I recognize body

image dissatisfaction is present among most women, I believe body dissatisfaction is uniquely experienced for each woman and within each experience are intersections of class, health, ability, and ethnicity. My experience is privileged and representative of only my life. The researcher's "inherent subjectivities" ought to be viewed as central to the research project (Campbell & Wasco, 2000, in Hewitt, 2007, 1149), and my goal in disclosing my social position is to place my knowledge and limits of experience to the forefront of the research process.

I have outlined my social position and the tension or fear established because of my theoretical alignment and the importance of the researcher's presence in the research process. It must be noted that I identify as an outsider to the HIV community. Although I am a woman who has experienced body dissatisfaction, I may not be acknowledged as an insider of this gendered knowledge. Insider status is not easily attained or described, appearing to be in flux depending on the community and other factors (Lasala, 2003; Greene, 2009). As an outsider to the experience of body image in conjunction with HIV, I considered whether my experience with body image would be valued or if I would be viewed as an outsider researcher only. Much is written about this tension. The interviewer, Bhopal (2001) wrote, may have difficulty in building relationships with participants, understanding the complexities of the social issues within the community, and gaining access to community members if perceived as an outsider. Wolf (1996) warned there are always unequal hierarchies of control that exist between the researcher and the researched. To be transparent with participating women I disclosed of my outsider

status at the forefront of the interview and stated the research sought to learn from and give voice to their insider stories shared during interviews rather than my voice. It is through this transparency that I feel I was allowed to hear stories. By placing myself in the research, I hope to have practiced a less oppressive approach to interviewing and research.

Journaling was also a crucial piece to my reflexive practice. From the first semblance of a research question, I began to write personal entries that included thoughts related to the topic of body image, marginalized women, feminism, postmodernism, and HIV. Journaling truly took shape as I began to plan for and conduct interviews. At this process my concerns about my outsider status, power, and uncertainty emerged. I was very unsure of how women would react to me and whether women would share stories with me. Upon conducting interviews I purposefully planned time after each interview to reflect and journal on the experience. I focused on feelings I had during the interview, uncomfortable moments, and any connections I could make to prior reflections, literature, or other interviews. These passages are very important to keeping me centred on how I was feeling in the moment of each interview. I really value each entry and the passages of my journal allow me re-live moments of realization.

Ethical Considerations

The dissertation received ethics approval from the Research Ethics Board at McMaster University after submission of a formal ethics application. Confidentiality was assured to participating women by securely holding paper and electronic files, and by removing identifying information from all forms. Information with names and contact information were stored in a locked cabinet and on a locked computer. Only I was aware of the personal information of the participating women and I kept this information confidential. To further this assurance, women were offered their choice of pseudonym to replace identifying information. If a pseudonym was not chosen, I inputted a random name to the transcript. Informed consent was obtained by providing necessary information of the research process, purpose of the study, and by obtaining appropriate permissions. Upon initial contact, interested women were notified of the study and were provided space for dialogue about arising questions and concerns. Plain language was used in the documents but also during conversations with women. Voluntary participation was achieved by means of recruitment processes and assurances of withdrawal procedures. Women were recruited through posters and were notified the study would neither benefit nor detract from their present services at the poster location. Further, I clearly stated to the participating women that they could withdraw from the research process at any time and could request to have record of involvement in the research destroyed. Participants were notified their withdrawal from the process would not affect the honorarium received for participating. According to the *Tri-Council Policy Statement* (2010) and Martin & Marker (2007), the risks arising from the study should be no greater than those encountered in daily life. I took this responsibility very seriously, especially when reflecting on

disclosure fears and the stigma attached to HIV-positive status. To ensure risks were minimized I encouraged participating women to choose a location for the interview that was private and within which they felt comfortable. Further, I took great care in protecting identities of participants, and removing identifying information.

Power

Ethical considerations must also include a focus on power relationships. As an academic, and identifying myself as a Master's student, I immediately engaged in a power dynamic based on my academic and professional credentials. Even though I have no lived experience with HIV, I was seen as a knower because I was doing research. My presence in the research process was a source of ongoing reflection. I tried to remain constantly aware of how I was affecting the stories that were being shared and how each woman was relating to my presence. Two experiences stand out as identifying features of my presence in the research process. The first was experiences of women comparing their bodies to mine. My body was present in the interview and there was no way to hide it. So while I could create space and step away from the interview process with my voice, my body was not able to step away. Many women used my body as a reference point to past weight, Tweety said she was "smaller than I was" prior to diagnosis, and Danielle used me as a reference for "skinny". These experiences made me feel uncomfortable. It felt as though an assumption was being made about my body and about my relationship with my body. I spent much time reflecting on my HIV negative status but not on my own size; in fact I

thought sharing bodied experience would grant me access as an insider to the body image portion of the research. The women opened my eyes to a world in which my body was a representation for something I did not see, but that other women felt. Not only was I an outsider researcher, but I presented with a body that represented the former shape, or “skinny”. A second prominent reflection was related to my power as a researcher. After completing the interview, Ani asked me if she answered my questions adequately and did “okay”. It then dawned on me that this is an example of the power imbalance I had tried so hard to minimize in this research process. This woman was looking for approval from me and was hoping to gauge my value of her stories. I left questioning what more I could have done to empower her as an expert from the beginning and to minimize my role as a supervisor of the interview. Both experiences left me in wonder and reflection.

Chapter Three:

Findings

The findings represent the narratives that emerged from each qualitative interview. Each story emphasized the unique experience and personal meanings of HIV as it related to women's relationships with their bodies. While each story was unique, certain commonalities emerged that resonated across all stories, and spoke to the larger narrative of female body image within the context of HIV. The findings have been organized into three overarching narratives. Within each narrative are stories that help to tell us more about women, body image, and HIV. This is a compilation of the stories shared by six remarkable women. It is my hope that I highlighted their emotions and experiences in a way that paid tribute to their time and efforts spent taking part in this project.

Narrative One: The Body Prior to HIV

The first set of stories that the women shared with me were about the relationship constructed with their bodies as young women. Two common threads emerged: 1) stories of past relationship with their bodies and 2) the social and cultural influence on the construction of the relationship with their bodies. These stories spoke to the narrative of women and the way women experience their bodies.

Past Relationship with the Body

“I would say like (I had) a perfect body”.

Within the larger narrative of women’s experience with body image, women told stories reflecting on their past relationship with their bodies. Stories were heard of women feeling “comfortable” with the relationship with their bodies in the past. Tweety shared she had an eating disorder in her youth, but stated, “my body was fine, healthy and I say like I was really ‘thin’ or ‘skinny’”. Similarly, Ani stated,

“When I was young I was really happy with my body... I would define myself as skinny, not saggy... Um like I have always been very, very skinny even when I was young. I used to take size 3 and 4”.

Women equated comfort and satisfaction with the past relationships held with their bodies and used the word “skinny” to describe an ideal body. With each story shared that used the term “skinny” it became clear what power “skinny” had in the experience of women and body image.

Unlike other women, Asha did not describe her former shape in the language of “skinny”. She identified as a plus sized woman who was not focused on losing weight or being “skinny”. Her story offered an alternative point of view.

“I was big too so I had to get past being a certain size. Like you know if you’re 263lbs you’ve got to, but that was never really an issue”.

Asha spoke to having to get past being a certain size. For her, even though she did not describe her past shape as “skinny” she had to move past the ideal in order to accept herself as a plus sized woman. Where many women seek a “skinny” identity, Asha’s story reflected a departure from the others’ experience with body image. Not all women sought or had the same form, but most women continued to experience body image concerns. Just like many women in Western society, the women in this study demonstrate the range of relationships that women have had with their bodies over time.

The Social Construction of the Female Body

“In Africa if you’re big you are considered more sexy... because someone who is skinny is dying”.

When speaking to women about the experience with their bodies, conversations on the larger structural influences placed upon the female body inevitably emerged. Some women had experiences with different cultures that supported alternative ways of knowing the female body, but also had experience living within a Western culture that expects thinness. Asha spent time in Africa where messages encouraged a larger female body. She shared,

“It is a totally different body image. In Africa if you’re big you are considered more sexy. You’ve got food and you can bear many children. So you are chased after like crazy where as here they are looking for that fourteen-year-old boy... You’re healthy and productive because someone who is skinny is dying... Culturally it is very different there”.

Danielle also shared a cultural image of women as being different than the Western model. She shared,

“My husband is Jamaican and ... Jamaicans don’t care about your weight. They love you big or small; in fact most of them love you big”.

The stories Asha and Danielle share highlight how standards of beauty vary across cultures. In other cultures women are beautiful if they are larger as it means they can bear children, are wealthy enough to have food, and are “healthy” as opposed to “dying”. In Western culture, women’s bodies are minimized to a small form that is deemed beautiful and healthy.

The women who were raised in a Western context, and whose standards of beauty were constructed within this context, highlighted how western conceptions of beauty are all around us. For example, Danielle stated that,

“I think it’s more acceptable for a man to be overweight than a woman. I think you don’t see a lot of people picking on men who are overweight rather than you just see it on women on shows. On TV shows you don’t find many big women that are looked up as being pretty”.

Danielle’s experience with Western culture is one in which women living outside the cultural ideals are portrayed as unattractive. As a self identified “big” woman, Danielle must navigate through cultural messages of what is “pretty”. Danielle asserted there is a

difference in the experience of cultural pressures and the female body for “skinny” women and “big” women.

The past shape of women’s bodies acted as a source of knowledge of what their bodies, and the relationship with their bodies, should look like. Layered narratives were discovered through comparisons to other cultures, and the dichotomy between “skinny” and “big”. Each woman’s story highlighted the juxtaposition between the past body and the relationship formed with their body at that time. These stories illustrated what it means to be a woman and experience the female body in Western culture.

Narrative Two: The Body Post-HIV

The six women who shared their time and stories also spoke to a change in the relationship they had with their bodies after receiving an HIV-positive diagnosis. These stories were diverse, but common threads emerged that tied the stories together to form a layered narrative. The common threads included were: 1) redefining the relationship with their bodies post-HIV, 2) the intersection of medicine with their bodies, 3) changing their bodies post-HIV, and 4) HIV-related stigma.

Bodies Re-Defined

“Help me... I kind of feel like I couldn’t go unnoticed before with the big boobs and red hair, and now I can’t get noticed”.

A common thread of stories of the women's relationship with their bodies post-HIV reflected conflicted feelings for the present body because of physical changes women attributed to HIV. Each woman spoke to the change in the relationship with their bodies as negative and described how their bodies have transformed over time.

Some women attributed a change in the relationship they form with their bodies to HIV because of the emotional impact it had on their life that resulted in increased eating. As a young woman it was very important for Tweety to be skinny and this carried on into her adulthood. However, following a diagnosis of HIV she began to gain weight. She spoke to how her "tummy" emerged after she was diagnosed with HIV. Throughout our conversation on her body it was her "tummy" that was of focus of her discontent. Her newly present "tummy" was in the way of feeling attractive, trying on clothes, and finding clothing she felt comfortable in.

Like Tweety, Ani also focused on her stomach. After being diagnosed with HIV, Ani gained weight and noticed it most in her stomach. She said her stomach,

"Looks like I am pregnant... some people will say are you pregnant? I say no I am not. It's just I gained a little bit there. I still have an ok body but ... all the fat goes here to my belly. And I hate it with a passion ... it is very hard to lose".

Danielle shared negative feelings for her body that were directly related to HIV. She spoke to physical change in her body as a result of depression at the onset of her diagnosis.

“I struggle a lot with being overweight, so that kind of puts a damper on my self esteem. At first I thought I was dirty and disgusting, and just knowing that it’s inside of me. It depressed me so when I am depressed, a lot of people when they’re depressed don’t eat, when I am depressed food is my comfort so... I mean it’s not so bad now but when I was diagnosed it was pretty rough. So that’s all I did was eat, eat, eat”.

Danielle experienced negative feelings for herself after receiving an HIV-positive diagnosis. To cope with feeling “dirty and disgusting” she found comfort in food and subsequently gained weight. Weight gain presented a new struggle and a new relationship with her body.

Asha focused on a loss of weight since diagnosis. She shared,

“Now you don’t know what to wear. You find yourself in Cotton Ginny plus looking for clothes and you need size four pants when you used to be close to a 40, actually I was a 42 once, and then a 40... So it is re-learning your style”.

When Asha lost weight she had to form a new identity, to re-learn her style as a “skinny” woman. She had to purchase new clothes to fit her new form. The body she knew before was a source of knowledge to her own identity and after a change she had to gain new knowledge in order to seek self-acceptance. Furthermore, when asked for a term or saying

that reflects her feelings for her body post-HIV diagnosis she said she felt “invisible”. This was echoed by Bobby who shared her experience of living with HIV has created the feeling of invisibility. This spoke not only to her bodily experience, but also the larger narrative of HIV and how it comes to affect the individual person and body.

Each woman experienced change to their bodies after HIV diagnosis and subsequently had to re-construct a relationship with their bodies. Whether it was Asha and Elaine’s concern about loss of weight, or Tweety’s concern about her stomach, their stories spoke to the larger narrative of female body dissatisfaction in that they experienced challenging relationships with their bodies.

Medicine and the Body

“You don’t want to not take something that might save your life”.

Medication and the effect this had on their bodies was a central feature of the stories about transformation of the relationship with their bodies after an HIV diagnosis. For most women HAART begun immediately after diagnosis and each woman’s story of medication expressed fears about HAART and the serious side effects incurred.

HAART had transformed Asha’s body and she described the transformation as,

“Wrinkles... from losing weight... I think it has a lot to do with the meds. I am on the meds. Probably the 6th round. It makes you sleepy and kind of makes you fuzzy upstairs. I had some that gave me severe diarrhea, I went off it ...”

Asha shared the medication caused her to lose weight and gain wrinkles. The changes to her body caused Asha emotional unrest and created a new relationship with her body. She compared her HIV-positive body to a “lost angel... with ratty wings” trying to find somewhere or something that “fits” for her. She attributed the experience of HIV to “ratty wings” that restrict her from finding a place where she feels she “fits”. She focused on how HIV had changed her body shape, a change best visualized by saying “your earrings and your socks fit” at a time when nothing else pre-HIV did. This is because Asha experienced such severe weight loss that she could no longer wear the clothes she used to.

Elaine also noted side effects of the medication that altered her physical appearance.

“My bum and chest... like I said I never really had an issue with my body until now. In my thighs I need to get it, like all the pants that I wear (gets up and shows the researcher her baggy pants on her thighs and bottom), like right here I just got no meat there (laughing)... but with the face I feel ever since I’ve been diagnosed it’s always been right here (pointing to cheeks) it’s been hard to fill (laughing)”.

Bobby shared that she has incurred many of the side effects of the medication that included both weight loss and weight gain. Bobby described this as her “body going through changes”. She described what changed about her body,

“See the hump on my back? This pad of fat here? I never used to have that before. And my skinny legs... It’s like my whole face has changed shape... now all of my fat is in my, like the worst place for anybody to have it really, around my belly... and now I am losing my hair, it’s like oh a bonus”.

For Bobby medication severely transformed her body. Bobby experienced the most change to her body of all the women I spent time with. The physical changes Bobby experienced were negative and had a negative effect on her relationship with her body.

Women also spoke of medications and the difficult decision of whether to take medications. Ani shared her experience of HIV medication and the perceived severe effect on her body,

“Inside I look tired, because your body changes, your meds are strong, and you are very tired all of the time... You’re tired all of the time and you have a lot of fatigue ... when you take medication they have a lot of side effects so you have to weigh the side effects... So it’s really not easy I would say it’s hard. Because sometimes you will get sick from this pill and then, this pill is going to be good for you... And if you change your meds, always the med has side effects, so really it doesn’t matter what med you take”.

Ani’s story illustrated a conflict between taking medication because they can prolong life, but also speak to the negative experience of the pills and invasive side effects. Although effects were different for each woman, side effects of medications created a change in the relationship formed with their bodies. Further, women were torn between the idea of health as it equated to longer life and the idea of health as it equated to a body free of side effects from medications. Medication did not mean extended life exclusively, but also a

life based around medication, body change and body dissatisfaction, and feeling ill. Medication shaped the relationship HIV-positive women form with their body post-HIV diagnosis.

Changing the HIV-Positive Body

“I wish I could change my body. I wish there could be some magic that you could change it, but I know that’s not going to happen”.

Cosmetic surgery was mentioned as an option to change physical features that changed as a result of the side effects brought on by HAART. Elaine brought up the term “wasting” when she was describing the impact that medication had on her physical features. For Elaine, “wasting”, or facial lipodystrophy, resulted in the loss of fat in her face and the appearance of having sunken cheeks. This was so distressing to Elaine that at one point she considered Botox as a way to possibly change the appearance of her cheeks.

“This morning on the coupons thingy’s one of the sites was 50% off for Botox. I said ‘maybe I will try that’ (pointing to cheeks). Yeah I was thinking maybe this will fill this in and some other places... I think there is no stopping that, it just I don’t know, it just comes and goes as it pleases and there’s nothing that can be done unless you want Botox (laughing)”.

Other procedures that the women mentioned were having a “full body lift” or breast reduction surgery. Recently, Bobby sought medical help to remove a hump located on her back.

“There was a plastic surgeon in London that was sympathetic to HIV-positive people and she had just removed somebody’s hump. That’s terrible to say ‘I have a hump’. Isn’t that nice”?

Bobby was very disappointed when a plastic surgeon cancelled her appointment. She spoke of the difficulty in finding an “HIV sympathetic” surgeon in her hometown. The “hump” on Bobby’s back was a sign of HIV that Bobby wished to have removed.

Ani also sought help from her doctor for liposuction of her stomach and the wish for a solution to weight change post-HIV.

“One day I asked my doctor if he could give me the stuff to suck it in or whatever you want to call it. He said no because I am not 400lbs so he can’t do that. Plus it is very dangerous too”.

Cosmetic procedures emerged as a means of attaining an ideal defined uniquely by each woman. Like HIV-negative women, HIV-positive women saw cosmetic procedures as a way of obtaining former or better bodies and more significantly, bodies that did not look HIV-positive. Unlike other women the changes incurred over time were a result of HIV and the practice of cosmetic surgery for HIV-positive women may be less about vanity and more about appearing healthy.

Stigma, Relationships and the Body

“What are you going to do now? You can’t have sex because you’re HIV-positive; you know who’s going to want you”?

Stigma and the relationship it played in the construction of body image were shared through stories about romantic interests, disclosures of HIV-positive status, and the stigmatizing reaction from others. Women shared disclosing of HIV-positive status to a potential romantic interest was very difficult and was tied to their relationships with their bodies.

After her husband passed away, Ani had to re-enter the world of dating, but now HIV-positive. She shared,

“To get a relationship it’s hard because you have to tell your partner that you’re HIV... Well I think it’s hard... when you meet somebody and you don’t know the person and then by the way I have to tell you that I am HIV. You don’t know how the person will react. They can say okay or they can say forget it”.

Ani’s experience with forming new relationships was one tied to her identity as “HIV”. Ani’s fears of disclosure resonated in stories from other women. HIV was deemed as something to be feared by others due to stigma. Ani’s experience of disclosing represents an overarching fear of negative reactions from others because of the stigmatized status of HIV.

Asha referred to the act of disclosing to a romantic interest as “psychological, it’s climbing the mountain”. She shared,

“Well when you meet somebody, and you’re interested, how do you tell them what you got because people don’t understand it and they say ‘oh you’re clean’ ... I have had guys freak when I told them I was positive... If the interest is there then I disclose ... Nobody wants to have sex with you”.

Asha’s story spoke to the larger narrative of HIV and the body that includes a dichotomy between being clean, as attributed to being HIV-negative, versus HIV labeled as dirty or unclean. Asha’s experience with men enforced this idea of cleanliness and made her feel that others view her body as dirty. This story highlights the psychological impact stigma can have on HIV-positive women’s experience with her body in the context of relationships and sexuality.

This was echoed by Bobby’s sharing of her experience of thinking about romantic and sexual relationships as an HIV-positive woman.

“Because I just feel like my body is so messed up and I tell myself that’s really vain in a way because there are quadriplegics who find love, every kind of person finds love but I’m always like I wish I had a boyfriend when I was infected or a husband when I found out then I would already have someone”.

Bobby described her body in this narrative as “messed up”, and suggested that the HIV-positive body can be compared to a physical disability, or marker of difference. By

juxtaposing HIV and physical disability Bobby spoke to the level of HIV-related stigma she has experienced in the past and fears related to future opportunities. Like all of the themes associated with HIV, stigma is present and difficult to conquer. There is a fear present in each story and the fear centres on how others will perceive HIV in their bodies.

Narrative Three: Fluid Stories of the Body Over Time

Although two questions were asked, and I assumed two dominant narratives would emerge from these questions, I was surprised to hear three overarching narratives from the stories of HIV-positive women. The stories that the women shared were non-linear; in some moments the relationship with their bodies was spoken of in the present and also reflected on in the past and some stories were reflections of the relationship with their bodies in the past from the present meaning attributed to their bodies. The first narrative emphasized the relationship women constructed with their bodies in the past and the second narrative described the relationship women have constructed with their bodies since receiving an HIV-positive diagnosis. This narrative moved through time, forwards and backwards, and included deep reflections on how the present relationship with their bodies can re-define past relationships with their bodies.

Mourning the Body

“When I look at pictures of myself now when I was younger ... I think what a beautiful girl, like it's somebody else. But I didn't feel like a beautiful girl then”.

Some stories illustrated a changed relationship with their past bodies because of present experiences. Although Bobby didn't idealize her body prior to diagnosis, the changes to her body that were impacted by HIV-resulted in her viewing her past form in a new light. Pictures of Bobby pre-HIV surrounded us in her living room, and were there to be viewed by any visitors she had. The pictures were set up almost as a memorial for what Bobby described as her "old" body. As Bobby described the loss of her former features in her living room, it was evident that each picture displayed represented a past that she wanted to be seen and not forgotten. She brought me a picture that showed a young woman who appeared so confident in her body, with long red hair showering her shoulders and a very feminine body. Yet, as Bobby showed me these pictures with what I believe to be a sense of pride based on her glowing description of each picture and beaming smile, she also said,

"I always felt overweight... I didn't like my body before, now I would kill for my body".

Bobby's story told of her experience with her body in the past, but also how she experienced her body in the present time. Bobby did not have a positive relationship with her body in the past yet she described her past form as positive in the present. Bobby stated she wished she had her prior body now and spoke of her past form as an attractive female body. As Bobby's body changed and she experienced the effects of HIV, her

relationship with her body was altered and she was able to re-evaluate and reform her feelings about her past shape.

Asha shared a reflection of her body today, from the position of her past expectations. Crying, Asha shared “I always wanted to be this small but it’s not going to turn out the way I wanted it to”. Asha’s story also spoke to the changes her body has incurred since her diagnosis, but also to her past ideas of what her body should be.

Although only two women explicitly stated they re-defined their relationship with their bodies from the past, other women shared similar stories. Tweety described her struggle with an eating disorder as a young woman and shared she wanted to be “smaller”. When reflecting on her past body from her present relationship as an HIV-positive woman, Tweety described herself as having a “perfect” body and being content with her body then. In retrospect her past body seemed more positive than she may have experienced it at the time. The present struggle in constructing a relationship with their bodies allowed women to re-define their past relationship with their bodies as more positive than was actually experienced at that time. This contextualized reflection come from a tension between the past and present hopes and realities.

The Ideal Body as a Number

“I was 169 and that was the biggest I have been since I was 192, I am usually around 160 and I would love to be back down to 150 or 140 but I will never be that”.

Many women shared stories that focused on specific numbers for attaining an ideal body through weight management. Interestingly, these stories were told in a position not obstructed by time. Stories included reflections from present weight on past ideals for their bodies. The numbers used by women were tied to HIV and health, and were shared to highlight the change HIV has had on their bodies. For four women a static number emerged as representative of the ideal body, and was compared against the present frame.

For Elaine this meant gaining weight. Elaine stated,

“I got to 132 but I was okay. I could have toned it up again. I would be happy with 120. I am not going to go nuts if I don’t get to 120 but as long as I look healthy”.

Bobby shared a recent experience of being weighed at an appointment.

“I got weighed at the endocrinologist and I was 169 and that was the biggest I have been since I was 192, I am usually around 160 and I would love to be back down to 150 or 140 but I will never be that”.

For Tweety and Danielle weight loss was the main focus. Tweety shared,

“I want to kind of go back down, not under 100lbs, probably maybe 120 or 130. I want to be back at that weight and lose the tummy”.

Danielle based her weight loss goal on her size when she met her partner.

“I was 140lbs when I met my husband. I would love to be able to lose, now I am 250, so like 100lbs”.

Numbers emerged as a ruler for body acceptance. 120, 130, 140, or 150 became standards of beauty marked in a quantitative form. What informed standards for women varied, but for each woman the number changed with HIV and the number sought was closer to a model of health that did not represent HIV-positive status. Women reflected from their present experience with their bodies on an ideal body weight from a past time. The fluid reflections of the body from the past to present, and from present to past, were a surprising finding. These stories highlight that HIV affects body image in the present and past. Women reflected on their past bodies, as HIV-positive women, in a new way. The intersection of HIV and body image allowed women a new perspective in exploring the meaning of their past and present relationship with their bodies.

I spoke with six women who were passionate and eager to share stories of the complex relationship formed with their bodies. The rich stories spoke to a challenging relationship with their bodies and parts of their bodies that changed after diagnosis with HIV. When speaking of the past, stories tended to emphasize the cultural ideal, and a body pre-HIV that could be measured in quantified form. HIV, however, thwarts the relationship with their bodies, and each woman told a story about their relationship with their bodies since becoming positive. These stories were about how the relationship with their bodies is re-defined post-HIV, how medication interacts with the relationship with their bodies, the yearning to change their bodies, and the experience of stigma as it relates to relationships

with others and the relationship formed with their bodies. Stories also included fluidity in the descriptions of relationships with their bodies that were not restricted by time. These stories highlighted past hopes, present realities, and a re-definition of the relationship with their bodies of the past all in one statement. Overall, the women's stories emphasized the unique challenges women living with HIV must face when constructing a relationship with their bodies.

Chapter Four:

Discussion

Strengths and Limitations

This study was not without limitations despite my intentions and efforts. Because of time and space constraints only 6 women were interviewed and a limited number of stories could be shared in this dissertation. I would have liked to include all of the women who were interested in participating and include the full stories of each woman who participated. Another limitation is the scope of the study. While I highlighted the intersection of women, HIV, and body image and included discussion of the acceptance of different forms of the female body in non-western cultures, other issues of marginalization such as the impact of racism and poverty on the women's lives were left out. Given the short length of the thesis and the time needed to closely analyze narrative data, I was unable to pay as close attention as I would have liked with regard to the impact of race and class on the women I interviewed.

I locate the strength of this study in the space it created for women to talk about their experiences. By choosing to have conversations with women based on narrative inquiry I was choosing to create space for women to speak about their relationship with their bodies and HIV. This process gave power to the women I interviewed. As a result the findings encompassed their stories, their words, and their voices. The interviews were

more like conversations in which I was not the dominant speaker. The narrative conversations allowed women's voices and experiences shine through. In analysis I resisted the urge to label and sort, opting instead to weave and provide stories that include the words of the women themselves. I hoped these practices were anti-oppressive and empowering to each woman who was included in the study.

Analysis of Findings

The women who participated in this study were excited about having the space to talk about their bodies. This is not surprising given that HIV-positive women are rarely a focus of research (Gurevich et al., 2007). This thesis sought to include HIV-positive women's voices and focus on an experience that all women experience. Following the three dominant narratives that emerged from women's experiences with their bodies were three overarching issues: 1) the body as experienced by women, 2) HIV, stigma, and the body, and 3) fluid positions of reflections on their bodies.

The Body as Experienced by Women

The stories that began the findings were stories not about HIV, rather, these were stories about women's experiences with their bodies more generally. Women shared stories that idealized their former shape while denoting a troubled relationship with the body today. It was as though the former body was an example of what the body could be, but was no

longer. The former body was one that was “skinny”, “perfect”, and “comfortable”. The stories shared by women included language that spoke to what Bartky (2010) described as the “tyranny of slenderness” (p.87). Women’s used the word “skinny” to refer to an ideal body. The term “skinny” is rooted in cultural narratives that highlight the control of weight as the mechanism to an ideal female body (Hesse-Biber, 2004). Women spoke of their past bodies as positive because they fit into the definition set by the cultural narrative that strives to control the female body. The stories of women’s relationships with their bodies were about the past hopes of a “skinny” body. Skinny was a “perfect body” and a “healthy” body. In each story an ideal presented that was measured by the culture. The body was described as troubled if it is not “skinny” and literature suggested that most women experience a complicated relationship with their body (Silberstein et al., 1986; Young, 2005; Greenberg, 2010; Cash & Henry, 1995; Hartley, 2010).

The stories of the body pre-HIV also spoke to the social construction of the female body and to the often hidden structure of health that informs the relationship women shape with their bodies and dictates a very narrow idea of the female body (Hesse-Biber, 2004). The stories of the body pre-HIV were stories of a body close to the culturally dictated norm and stories that described a positive relationship with the body when reflecting of the past. While I proposed a fluid understanding of body image, as it was experienced by each woman uniquely, I did not anticipate a conversation that described the fluidity of the female body based on cultural experience. This conversation explored the construction of female beauty in other cultures as it intersects with the sexist model of female beauty in

western culture. Asha's story highlighted the multiple ways women's bodies could be understood and valued. It was a story that countered the narrow Western model of the female body by including a focus on larger women. Danielle also questioned the dominant discourse within popular culture. In questioning the image of "big" women, she questioned the role of alternative forms of the female body. Her story spoke to the sexism present within popular culture, as did the literature that stated cultural messages are rooted in misogynist ideas and inequality (Brown, 1985; Young, 2005; Davis, 1997). While she voiced frustration with the dominant model of the feminine form she struggled to resist it by proposing her goal is to lose weight. Although the experience with sexist messages is frustrating, women still spend time tending to attaining the culturally mediated ideal. Literature suggested this time investment deters women from actively resisting the sexism present in the cultural model of the female body (Brown & Jasper, 1993; Attie & Brooks-Gunn, 1987, Hesse-Biber, 1996; Hesse-Biber et al. 2004). Tension was present in stories in which women struggled to voice frustration with the dominant model of female beauty, but also felt constrained to reform within the model.

HIV, Stigma, and the Body

The narratives shared of the relationship formed with the body post-HIV were centred on themes of changes to the body, medication, the yearning for cosmetic procedures, and the experience of stigma. The second narrative was different from the first in that it was about the intersection of female body image and HIV. HIV-positive women experience troubled

relationships with their bodies like HIV-negative women while also facing challenges related to HIV. While HIV-negative women anticipate certain changes to their bodies during their lifetime as a result of pregnancy, menopause, and aging, women with HIV go through many of these changes while also experiencing bodily changes as a result of HIV. Each woman shared a story about a body part or change to the body that emerged after HIV-positive diagnosis. Echoing studies done by Corless et al. (2004), Martinez et al. (2007), and Sharma et al. (2006), that found women had negative experiences with their bodies post-HIV, the stories women shared were about being challenged by changes to their bodies. When meeting individually with each woman and posing questions about troubled relationships with their bodies the questions were not contemplated for long. Each woman identified dissatisfaction immediately and gave examples readily, speaking to disconcerting experiences with the body that were exacerbated by HIV. Women's stories spoke to physical changes that moved their bodies away from the cultural ideal and their HIV-negative body. HIV-positive women experience negative feelings for their bodies as a direct result of HIV. It is as though HIV-positive women must live within the model of feminine beauty as all women do, but with greater challenges on the journey to body satisfaction.

Many women shared of their experiences with HAART and the difficult decision to take medication that has the potential to extend one's life, but also to make one's life more challenging. The women taking HAART shared stories about lipodystrophy's effect on their bodies that illustrated findings from the literature that stated HAART recipients are

likely to experience extensive physical side effects (Carr et al., 1998; Gervasoni et al., 1999; Falutz & Turcot, 1999; Carr et al., 1999; Lichtenstein et al., 2001; Carr et al., 2000; Thiebaut et al., 2000; Heath et al., 2001; Persson, 2004). These side effects informed the relationship women constructed with their bodies. The model of health from which the use of medication develops focuses on extended life as the goal while the model of health for the ideal female body does not encourage incurring these physical changes. These women seemed to make a decision as it related not only to their life as measured in years, but in quality as well. In taking medication they experience nausea each day, weight gain or loss, and other changes to their lifestyle and body. The medical power on the bodies of HIV-positive women was most apparent in these stories. Medicine truly shapes the lives of women taking HAART, in their daily routines, self esteem, and quality of life as described by the women in this study as well as the literature (Blanch et al., 2004; Dukers et al., 2001; Schrooten et al., 2001; Tate & George, 2001; Wagner & Rabkin, 1999; Maus, 2002; Collins et al., 2000). It's as if control over the body is removed and women are left to live with various physical changes to improve health.

The changes to the body post-HIV diagnosis were addressed by some women through dreams of cosmetic surgery. The narrative of body dissatisfaction and cosmetic surgery was reminiscent of women who are not HIV-positive. I refer to the extent that many women go to in order to preserve youth, such as receiving Botox injections, face lifts, etc. to alter the aging body. As literature on female body image suggests, the strive to fit within a model of youthful, feminine beauty is present for all women and this often

includes contemplating the possibility of plastic surgery to change a body that is deemed flawed (Leon et al., 1993; Stice, 1994; Peterson et al., 2006; Hartley, 2010). Cosmetic surgery was present as an option for HIV-positive women as a means of obtaining a better body, but I question whether this was attaining the ideal female body or something more. Could it be that HIV-positive women want to change their bodies to remove the physical signs of HIV? Certainly all stories about cosmetic surgery were about changing physical effects of HIV such as “buffalo hump”, “wasting”, and liposuction to remove weight from lipodystrophy. The stories of cosmetic surgery spoke to a hope of controlling the body that is presented to others. For HIV-positive women, cosmetic surgery may be more about changing the HIV-positive body rather than changing the body to fit into female beauty standard.

While I did not initially foresee romantic relationships as a factor in the construction of body image for HIV-positive women, it was apparent through stories that body image for HIV-positive women was tied to stigma as it was experienced through relationships with others. The pressure to disclose and the subsequent reaction from men shaped the women’s feelings of HIV as it related to how they feel about themselves and their bodies. By disclosing of their HIV-positive status to others women were adhering to the discourse of risk management and “bio-power”, both of which encourage HIV-positive women to control the spread of HIV through sharing their diagnosis to others (Foucault, 1979; Persson et al., 2003; Caldwell, 2007; Keenan, 2001; Sawicki, 1991; Tangenberg & Kemp, 2002; Galvin, 2002; Reissman, 2010; Wilson, 2001).

Stigma and its relationship to the female body were most apparent in these stories about the negative reactions the women experienced when they disclosed their HIV status. The reactions, from men in particular, made the women in this study feel “dirty”, “messed up”, and speak about their bodies as undeserving of a relationship. The narrative of feeling “dirty” was represented in the literature and is a common story of HIV-positive women (Patton, 1994; Gorna, 1996; Lekas et al., 2006; Siegel & Lekas, 2002). As Goffman (1974) suggested, stigma is a body that is discredited and deviant. Hence, the women’s experience of feeling “dirty” could be related to the internalization of how others discredit their bodies. As the literature suggests, when women are immersed in negative reactions from others they internalize that stigma and the judgment of their bodies (Lekas et al., 2006; Siegel & Lekas, 2002; Lawless et al., 1996 in Gurevich et al., 2007). The cultural discourse that stigmatizes HIV was highlighted in women’s stories about their romantic relationships and subsequent internalization of HIV-related stigma.

Fluid Relationship with on the Body

The women’s stories weaved back and forth between pre-HIV and post-HIV narratives about their body image and were, therefore, stories of both the present and the past. Postmodernist literature suggested stories, experience, and knowledge “can be characterized as changing and fluctuating according to the context of feelings, content and ideas expressed” and this was evident in the third narrative (Weiner-Levy, 2009,

p.734). This was reflected in the women's narratives as they described their bodies from the past to the present, and from the present to the past. Women were able to speak to the past and present all at once, in the same sentence. Asha's story was an example of this: in one sentence she talks about what she wanted in the past, what she has now, and shares frustration about past hopes and present realities. Bobby's story also highlighted how a relationship with the body in the present can re-shape the relationship with the past form. It speaks to the fluidity of stories and the denouncement of a meta-narrative of the female body. These stories and the literature suggest women experience their bodies each day from multiple positions, based on various experiences that are always changing, and allowing women to change their relationship with their bodies without limits of time (Fallon & Ackard, 2002). Women were challenged by their bodies in the past, are challenged by their bodies today, and when they reflect on their bodies in the past today there might be yearning, idealization or loss, but it was in today's perspective that this could be seen. For women, this meant that their relationship with their bodies in the past was altered by their present relationship with their bodies. Body image is a process that is active (Gleeson & Firth, 2006) and the women I interviewed experienced a fluid relationship with their bodies. These stories moved through time non-linearly, these stories were circular, and there was no clear beginning or end. Rather, each story was a reflection from multiple moments in time and represented multiple experiences.

It is evident that HIV-positive women experience body image concerns that are similar to most women living in Westernized cultures. However, the impact of being diagnosed

with HIV, the side effects of medication, and the stigma of living with HIV result in unique challenges for women living with HIV. This suggests that the dominant model of female beauty affects HIV-positive women and shapes more than just feelings for the body, it shapes the lives of women. Together, the impact of HIV medications, cultural and social constructions of beauty, and HIV-related stigma resulted in participants yearning for ways in which to change their bodies through weight loss, weight gain mechanisms, and cosmetic medical procedures. The body of the past is described as more positive based on the relationship with the body today even when women experienced challenging relationships with their bodies pre-HIV diagnosis. These stories spoke to the reality for women living with HIV. To feel “invisible” or unnoticed speaks to the experience of receiving negative feelings towards HIV. When the re-defined body becomes one of discontent, feelings of invisibility are increased. These stories validated that body image concerns are indeed present in women living with HIV just as they are present for women more generally. Finally, women explored the relationship with their bodies through reflections from multiple positions based on the experience and time. These stories dismantled ideas of a grand truth about how women experience their bodies and suggested women’s relationship with their bodies is an active, non-linear, and fluid process.

Chapter Five:
Implications and Conclusions

Implications for Social Work Practice and Research

From the stories shared by women, implications emerged for social work practice and research. Future social work practice and research should consider the findings of this research when approaching work with HIV-positive women. The intersection of gender, HIV, stigma, and body image presents as a new domain of practice for social workers and other service providers. Feminist, postmodern, and peer based counseling are promoted as opportunities for practitioners to provide empowering and non-silencing care. Feminist social workers, in particular, are the ideal professionals to provide psycho-social care for HIV-positive women by ensuring that there is space to talk about the experience of being an HIV-positive woman that moves beyond the rigid format of traditional therapies (Greenspan, 1995). Feminist social work encourages challenging oppression within the therapy room making therapy a political and personal dialogue (Dietz, 2000; Brown, 1994; Sands & Nucchio, 1992). Therefore, feminist social workers are key to opening dialogue about HIV, women, body image, and stigma that extends beyond the therapy room.

Social workers and allied health and social care professionals should move away from the traditional models of therapy that pathologize body image and HIV. Postmodern

techniques can offer a more holistic approach through practices that externalize concerns from the individual thus removing labels and viewing the concern as a non-defining experience (White & Epston, 1989, 1990; Besley, 2002). Postmodern therapy also deconstructs and critically analyzes dominant discourses that are seen as the cause or the affect of the concern (Besley, 2002; White, 1991; Derrida, 1982). Externalization and deconstruction act to remove labels or concerns from the individual and instead challenge structural discourses. A narrative lens that removes the oppressive stigma and concern from the individual is paramount to respecting the expert knowledge of the individual while confronting larger discourse.

In order to address the marginalized and oppressed status of many HIV-positive women, insider support services should be explored. An alternative solution to social workers providing care is for peer support to occur in which one HIV-positive individual shares her own experiences and stories with another HIV-positive woman for the purpose of education and support (Harris & Larson, 2007). Peer support has been deemed both important and beneficial for HIV-related counseling and care as it facilitates the development of relationships within the HIV-positive community (Harris & Larson, 2007; Harris & Alderson, 2007; Hughes-d'Aeth, 2002; Molassiotis et al., 2002; Madray & van Hulst, 2000). Peer counseling would allow women to gain community support as well as decreasing isolation within the HIV community among women. Social work practice with HIV-positive women should consider feminist and postmodern approaches to care, as well as the role of peer support in service provision.

There are implications for future social work research based on the findings of this thesis and the stories shared by HIV-positive women. The women contributed stories of experiencing marginalization, stigmatization, and non-recognition in the HIV community. Feminist research pays attention to the role of power the researcher holds within the research process (Letherby, 2003). It is important for researchers to remain aware of their own power and privilege inside the interview room. Feminist research should be a guiding perspective to explore silenced and marginalized populations like HIV-positive women (Bhopal, 2010). Postmodern theoretical and methodological perspectives were crucial to creating the space to hear women's experiences with HIV and the intersection with their bodies (Reissman, 2002). The narrative based interviews allowed women to share their stories in their own way and using their own words. Future research with HIV-positive women should include space for open dialogue and participant empowerment. The women who participated in this study had strong voices, but I fear if not given adequate space they could have been easily silenced. From a feminist and postmodernist perspective I believe it is important that future research projects involve direction from HIV-positive women to ensure the academic focus is relevant to the life experience and concerns of HIV-positive women. The exploration of HIV-positive women's relationship with their bodies should continue to be researched to determine what HIV-positive women require to challenge the discourse of female beauty, HIV, and stigma. It is the role of social work researchers to make it a priority to focus on silenced populations and HIV-positive women have a lot to say about their experiences as women and women living

with HIV. Social workers have a lot to learn from HIV-positive women and should continue to create academic space for this learning.

Conclusion

The stories shared illustrated how women living with HIV experience their bodies and how HIV related stress and stigma can exacerbate the challenging experience of female body image. The stories questioned the dominant discourse of female body image and HIV as well challenging the traditional views of social work practice and research. Women experience their bodies in complex ways that are influenced by the social and cultural discourse of female beauty. With the onset of HIV, women experience their bodies amid new and complicated feelings brought on by HIV related physical changes to the body and stigmatization. Women's stories illustrated relationships with their bodies that were fluid and changing depending on time, experiences, and reflective positioning. This thesis is about body image and HIV, however, it must also be clarified that although I and many other women may experience body image concerns we do not experience the intersection of HIV and the female body.

I do not know what it means to live with HIV, to receive a life changing diagnosis, or to have to disclose of an illness that is so highly stigmatized. I do not know what HIV stigma feels like or what it feels like to not want to leave my home for fear of being outed. I will not know what HIV felt like for each woman, but I have been provided the

opportunity of sharing time with women who are HIV-positive and who felt I was worthy enough to hear their stories. Stories can be a means of speaking to emotions, struggles, and challenges that have previously been ignored or silenced. Once shared stories cannot fade away as their meaning carries forward. This thesis carries forward voices of women's oppression that should not be ignored and that should be heard as a unifying call for academics, practitioners, and women to challenge the dominant discourse of the female body and HIV.

Appendix A: Recruitment Poster



PARTICIPANTS NEEDED FOR RESEARCH IN HIV AND BODY IMAGE

I am looking for volunteers to take part in a study of women living with HIV and the relationship women have with their body.

You would be asked to take part in a one to one interview that will involve sharing experiences with body image and living with HIV. Questions will include:

*What was your relationship with your body prior to your HIV diagnosis?
How would you describe the relationship with your body since your HIV diagnosis?*

Your participation would involve one session, which is approximately ninety minutes, at a mutually agreed upon location.

In appreciation of transportation and child care costs; you will receive a \$25 in the form of gift card or cash

For more information about this study, or to volunteer for this study, please contact:

Michelle Gibson
Faculty of Social Work

(519) 495-6975 or
Email: gibsonmv@mcmaster.ca

This study has been reviewed by, and received ethics clearance through, McMaster Research Ethics Board.

Call Michelle: (519) 495-6975 Or email: gibsonmv@mcmaster.ca	Call Michelle: (519) 495-6975 Or email: gibsonmv@mcmaster.ca	Call Michelle: (519) 495-6975 Or email: gibsonmv@mcmaster.ca	Call Michelle: (519) 495-6975 Or email: gibsonmv@mcmaster.ca	Call Michelle: (519) 495-6975 Or email: gibsonmv@mcmaster.ca	Call Michelle: (519) 495-6975 Or email: gibsonmv@mcmaster.ca	Call Michelle: (519) 495-6975 Or email: gibsonmv@mcmaster.ca	Call Michelle: (519) 495-6975 Or email: gibsonmv@mcmaster.ca	Call Michelle: (519) 495-6975 Or email: gibsonmv@mcmaster.ca	Call Michelle: (519) 495-6975 Or email: gibsonmv@mcmaster.ca
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Appendix B: Letter of Information and Consent

DATE: _____

LETTER OF INFORMATION

A Study of/about HIV and Body Image



RESEARCH

Principal Investigator:

Name: Michelle Gibson
Department of Social Work
McMaster University
Hamilton, Ontario, Canada
(519) 495-6975
E-mail: gibsonmv@mcmaster.ca

Co-Investigator(s):

Faculty Supervisor: Dr. Saara Greene
Department of Social Work
McMaster University
Hamilton, Ontario, Canada
(905) 525-9140
Email: greenes@mcmaster.ca

Purpose of the Study

You are invited to take part in this study on women living with HIV and the relationship that they have with their body. I am conducting this research for a Masters thesis in the study of Social Work. I am hoping to learn about how living with HIV has changed or not changed your body image and how you feel about your body more generally. Furthermore, I hope to learn how cultural attitudes about HIV and the female body contribute to body image among women living with HIV.

Procedures involved in the Research

The interviews will be conducted at a mutually agreed upon time and place.

At the time of the scheduled interview:

1. You will be asked to share your thoughts, feelings and reflections on issues related to body image and HIV.
2. You will be speaking to a female researcher, one to one.
3. If given permission by you, I will audio record the interview and may take handwritten notes.

During the interview, I will be asking you two central questions about how you feel about your body, and your experience living with HIV. The questions asked will be:

How would you describe your relationship with your body prior to your HIV diagnosis?

How would you describe the relationship with your body since your HIV diagnosis?

Potential Harms, Risks or Discomforts:

There may be potential discomfort regarding the sharing of personal information. I will be asking you to share information about your life. If your life experience has been difficult or upsetting, you might feel discomfort at this time. Please remember, at any time during the interview you may request a break, to withdraw from the study, or to skip a question. If you find the interview to be a discomfort, I will inquire about support in your personal support system, such as whether you have someone you can speak to in confidence at home. Further, I will provide information on counselling services that are available to discuss any issues that interview might raise.

Potential Benefits

The research will not benefit you directly. Your contribution will provide insight into needed services for women living with HIV, as well as areas of further research. I hope what is learned from this research will be applied to increasing social services for women living with HIV.

Payment or Reimbursement (If applicable)

In appreciation of transportation and child care costs; you will receive a \$25 in the form of gift card or cash

Confidentiality

Your information will be kept confidential. I will ensure documents that identify you will be kept in a secure location, on a locked computer with password. In regard to records, audio transcripts and personal notes, a code or no identifying information will be assigned such as your name.

Every effort will be made to protect your confidentiality and privacy. I will not use your name or any information that would allow you to be identified. However, we are often identifiable through the stories we tell. It is therefore important to keep this in mind during the interview process. To refer to your information in the final report, I will use a pseudonym to refer to your information.

There are exceptions to confidentiality. I have a duty to report any threats to harm of self or others. This includes a report of child abuse.

Participation and Withdrawal

Your involvement in this study is voluntary, at any time you can withdraw from the study. Withdrawing can occur even after signing the consent form. There will be no consequences for withdrawing and you will receive compensation for participating. If you withdraw, data you provided will be destroyed immediately unless you indicate that the data may be kept and used. At any time in the process you can refuse to answer a question but still participate in the study.

Your decision to withdraw, or be involved in the study, will not affect your access to services.

Information about the Study Results

I expect to have the research completed by September 1, 2011. I will provide a summary of results to The AIDS Network of Hamilton ON and the AIDS Committee of London ON.

Questions about the Study

If you have questions or require more information about the study itself, please contact me.

The McMaster University Research Ethics Board has reviewed this study and this study has received ethics clearance.

If you have concerns or questions about your rights as a participant or about the way the study is conducted, please contact:

McMaster Research Ethics Secretariat
Telephone: (905) 525-9140 ext. 23142
c/o Research Office for Administrative Development and Support
E-mail: ethicsoffice@mcmaster.ca



Inspiring Innovation and Discovery

CONSENT

Date: _____

I have read the information presented in the information letter about a study being conducted by Michelle Gibson, of McMaster University. I have had the opportunity to ask questions about my involvement in this study and to receive additional details I requested. I understand that if I agree to participate in this study, I may withdraw from the study at any time. I have been given a copy of this form. I agree to participate in the study.

Signature: _____

Name of Participant (Printed) _____

I agree that the interview can be audio recorded.

 Yes No

 Yes, I would like to receive a summary of the study's results. Please send them to this email address _____ or to this mailing address _____

 No, I do not want to receive a summary of the study's results.

To ensure confidentiality:

 I prefer to have an id number used

 I prefer to be identified or have a pseudonym used. Please refer to me as _____

I agree to be contacted about a follow-up interview, and understanding that I can always decline the request.

 Yes. How to contact me _____ No

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