This article discusses the findings of a study exploring the relationship HIV-positive women have constructed with their bodies pre and post-HIV diagnosis. Literature, feminist and postmodern theory, and narrative inquiry directed the study. Stories revealed women construct complex and fluid relationships with their bodies shaped by cultural discourse of the female body, physical changes to the body following diagnosis, and HIV-related stigma. Stories encouraged non-silencing, and non-pathologizing social work practice and research. Findings validate that women living with HIV experience challenging relationships with their bodies.

In this article, I explore how Human Immunodeficiency Virus (HIV) impacts women’s construction of a meaningful relationship with their bodies. While there is robust research on body image, women and HIV that is rooted in positivist theory (see Sharma et al. 2006; Martinez et al. 2005; Plankey et al., 2009), there continues to be a scarcity in research that places importance on the experience of HIV and body image in the context of a postmodern and feminist lens. This paper is an exploration of the social, cultural and psychological impact of HIV as it relates to the female body through a postmodern and feminist lens. This paper describes the stories of six HIV+ women residing in Southwestern Ontario to illustrate the socio-cultural, medical, and individual forces that affect how women construct relationships with their bodies and how women find new meaning in their personal identity following an HIV+ diagnosis. This report will outline relevant literature and theoretical underpinnings, provide excerpts of the stories women shared and will conclude with a discussion on implications for future research.

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LITERATURE REVIEW

The topic of body image saturates research literature in disciplines from psychology and psychiatry to social work and sociology. While this study focuses on the experiences of women alone by excluding the experiences of men, it does not propose that men do not experience similar cultural and social pressures related to male body image and HIV.

Feminist researchers have asserted that Western culture enforces a beauty ideal that sets the standard of feminine attractiveness. Hesse-Biber (2004) wrote: “Western culture creates a metaphorical ‘measuring stick’ used by women as a form of self-control and judgment, to determine the value of their own bodies” (p. 208). As the center of control, the female body becomes the site of gendered inequality and discrimination. Prominent feminist writers have shared their views on gendered discrimination. For example, Brown (1985) wrote that the ideal female body is a “manifestation of misogynist norms flowing from a culture where women are devalued and disempowered” (in Hartley, 2010, p. 247). Numerous authors have suggested that the time and economic consumption involved in attaining the female body ideal distracts women from creating a space to express political interest, empowerment, and resistance against the oppressive discourses that relate to women (Attie & Brooks-Gunn, 1987, Hesse-Biber, 1996; Hesse-Biber et al. 2004). Wolf (1991) wrote about how cultural focus on thinness represents obedience and “destroys women physically while depleting women psychologically” (p.19). The influence of the cultural discourse of female beauty is pernicious. Silberstein and colleagues (1987) wrote that the body image dissatisfaction among women is so prevalent that it can be considered a ‘normal’ experience in female development. Likewise, recent statistics indicate that 75% of women over the age of 18 believe they are overweight (Hartley, 2010, p.246).

Similar to the effects of the cultural discourse of the female body, the cultural discourse of HIV has significant effects for HIV+ individuals. 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’... sexuality, and deviance” (p.238). The use of Goffman’s (1974) term ‘stigma’ is rampant within research on HIV. Experiences of HIV-related stigma were highlighted in various studies that found women living with HIV are labeled as “dirty, diseased, and undeserving” (Lawless et al., 1996 in Gurevich et al., 2007, p. 13). The experience of HIV-related stigma can be internalized. For example, Lekas and colleagues (2006) found that women living with HIV “used terms like leper, contaminated, walking disease, and a germ
to describe how they perceived themselves” (p.1188). Similar to the discourse of female beauty, cultural ideas of HIV affect those who live with HIV, both emotionally and psychologically.

Research on HIV involves an understanding of HIV medications and their interaction with the body. Often people living with HIV are prescribed a drug combination called Highly Active Anti-Retroviral Therapy (HAART). Although HAART has the ability to reduce HIV symptomology to an undetectable level, and has led to decreased AIDS related mortalities, it carries with it severe side effects (Volberdin, 2003; Wynn, et al., 2004; Persson, 2005). Side effects of HAART are extensive and debilitating, and include lipodystrophy, weight gain, and weight loss as part of a broad spectrum of body alterations (Grinspoon, et al., 2003; Ridolfo et al., 2000; Plankey et al., 2009). Carr (2003) describes 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. HAART has diverse side effects that affect each individual uniquely, however, many of the individual side effects are severe. The findings illustrate the special challenges women living with HIV must face when constructing a relationship with their bodies.

THEORY

Two theories, feminism and postmodernism, directed the current research process. Feminist epistemology was an ideal fit with the research focus in two ways. First, feminist theory allowed for the exploration of the relationship women have with their bodies as an issue that is both personal and political (Bhopal, 2010; Campbell & Wasco, 2000; Letherby, 2003). 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). By identifying body imaging as a gendered and political process, feminist research allows for space to challenge the patriarchal structures that attempt to control women through the discourse of beauty. Second, feminist theory emphasizes a social justice oriented inclusion of women living with HIV and the stories of women who are often marginalized.

Postmodernism provides a second set of values that propose anti-oppressive and critical approaches to social work research. Postmodernism provides space for valuing alternative forms of knowledge such as emotion, imagination and experience (Neuman, 1997, p.82). Postmodern tenets shaped the current research in two ways: first, I aligned with the postmodern view of stories as “changing and
fluctuating according to context” rather than viewing stories as sources of concrete truth (Weiner-Levy, 2009, p. 734). Second, by adopting a deconstructionist view, I was able to challenge the rigid cultural pathologization of HIV and body image. In the current paper, HIV is viewed as a “transactional web of lived experiences, social discourses, and institutional medicine” (Persson, Race & Wakeford, 2003, p. 398). Similarly, body image is viewed as an active, fluid process influenced by multiple forces and by the social positioning of individuals (Fallon & Ackard, 2002; and Gleeson & Firth, 2006). In this paper, the use of the term ‘body imaging’ and the phrase ‘relationship with their bodies’ is guided by the theoretical choices.

When conducting research on HIV and body image, Foucault offers an approach to examine the modes of control on women and their bodies. He identifies social and cultural discourse of female beauty to produce “docile and disciplined bodies” by individualizing problems. In turn, individualization acts to normalize a disciplined lifestyle to maintain control (Foucault, 1979, p.28). 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. Foucault’s (1973) theory of ‘bio-power’ is instructive for the exploration of HIV and medical control of illness. “Bio-power operates at the macro-level of regulation by diffuse networks of institutional authority which seek to exercise control of populations by regimes of expert knowledge which measure, monitor, normalize bodily behaviours from individual sexual conduct to one’s inner desires” (Foucault, 1979, p.25). Women living with HIV have experienced extensive medical testing and continue to face medical control in the form of pharmaceuticals and other controls of disease transmission.

For Foucault (1979), power is built from knowledge, and in different ways, is exercised by all. In addition to medical control, the individual also imposes self-control to adhere to the social discourse of appropriate behaviours and health. Thus, it can be argued that women living with HIV are encouraged to conform to medical prescriptions and socio-cultural ideas of what it means to be a woman through both internal and external pressures. Thus, Foucauldian theory, as well as feminist and postmodern theories are relevant to the research topic, and has guided every step of the current research process.

METHODS

Narrative inquiry reflected feminist and postmodernist tenets of the study. Narrative inquiry also allowed for the creation of space for silenced voices, and the opportunity to explore multiple truths through
stories of lived experience. 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). Qualitative interviews were chosen in order to create an open, discursive space that supports a narrative approach to data collection and analysis. Leavy (2009) describes qualitative research as “composing, orchestrating, and weaving rather than merely gathering data and writing a summary” (p.10). By asking just two questions—how would you describe your relationships with your body prior to receiving an HIV+ diagnosis and how would you describe your relationship with your body after receiving an HIV+ diagnosis—more time was allocated to listen to women’s stories and expertise. 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 incorporates reading the data on multiple levels. This tri-level analysis is useful because it gives voice to the fluidity of experiences and knowledge of the women by paying attention to the storied nature of the interviews. Approaching analysis this way gives power to the story of the participant thus “privileging the participants’ positionality and subjectivity” (Reissman, 2002, p.3). In conducting narrative analysis, the final writing reflects 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.

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 at London and Hamilton, Ontario cities. Participating organizations agreed to post recruitment posters and distribute letters of information to interested participants. The women who participated in this study were affiliated with the participating service organizations or received information of the study from their own 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 a $25 honorarium for participating in the study. The participants’ ages ranged from 30 to 49 years. The women reported they have been living with HIV for two to 25 years. One woman identified herself as South American, and the remaining five women identified as Caucasian/Canadian. While I hoped to receive a more geographically diverse sample that included women from Hamilton, it became evident that the HIV/AIDS community in London was more receptive to the study.

The study received ethics approval from the Research Ethics Board at McMaster University. 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. To further this assurance, women were offered their choice of pseudonym to replace identifying information. If a pseudonym was not chosen, a random name was inserted into the transcript. Prior to the interview, a letter of information was shared with the participating woman that included the purpose, goals, risks, and benefits of the research project. 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 a safe space for dialogue, raising questions and concerns. Participants were notified that their withdrawal from the process would not affect the honorarium received for participation. According to the CIHR (2010) Tri-Council Policy Statement and Martin & Marker (2007), the risks arising from the study should be no greater than those encountered in daily life. To ensure risk minimization, I encouraged participating women to choose a location for the interview that was private and within which they felt comfortable. I took this responsibility very seriously, especially when reflecting on disclosure fears and the stigma attached to HIV-positive status. Throughout the data collection process, I focused on being sensitive, provided the opportunity to withdraw, extend support, and feel connected to me as a person, not as merely a researcher.

Stories of the Female Body & HIV

The findings represent the stories shared by women during interviews. While each story is unique, two overarching narratives emerged that help to tell us more about women, body image, and HIV.

Stories About the Female Body: Within the larger narrative of women’s experience with body image, women told stories reflecting on past relationship with their bodies. Most stories were about women feeling ‘comfortable’ with the relationship they had with their bodies in the past. Tweety shared that she had an eating disorder in her youth, but stated, “my body was fine, healthy and 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 they held with their bodies and used the word ‘skinny’ to describe an ideal body. With each story shared by participants that used
the term ‘skinny’ it became clear what there is a power ‘skinny’ has in
the experience of women and body image.

Conversations were also evoked about the beauty myth
perpetrated by Western culture. Danielle stated that:

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

As a self-described ‘big woman’, Danielle shared her experiences
navigating through cultural messages of what ‘being pretty’ means.
Danielle asserted that there is a difference in the experience of cultural
pressures and the female body for ‘skinny’ women and ‘big’ women.
This is indicative of a dichotomy created and maintained by cultural
discourses.

A story Bobby shared illustrates that the social construction of
beauty comes not only from cultural images, but also from family
narratives. She shared:

*You had to be attractive, there wasn’t anything else. Like you
know my mother…all she ever used to say was ‘what a beautiful
girl, doesn’t she have a great body?’ She never used to say ‘you
can be anything honey’.*

Amidst conversations about the female body, a layered narrative
emerged that drew on the dichotomy of ‘skinny’ and ‘big’, and how
beauty narratives can come to define how women see themselves. This
illuminates what it means for these women to navigate discourses of
female beauty, especially within the thin versus not-so-thin cultural
preferences.

**Stories About the Female Body & 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. Common
themes emerged in conversations about the female body and life with
HIV including stories of redefining relationships with their bodies, the
intersection of medicine with their bodies and the experience of HIV-
related stigma.

**Emotional impact of life with HIV:** For two women not prescribed
HAART, change to their bodies was related to emotional and social
challenges at the onslaught of the diagnosis. Tweety noted that it was
very important for her to be ‘skinny’; however, she described her body to
begin to take a new shape following diagnosis. Tweety shared a story
about how her ‘tummy’ enlarged because of her HIV-related social
isolation. “It was how much I was eating, because then you’re always at home and you’ve got more food around the house. So you’re always eating especially if you have cravings”.

Danielle also experienced changes to her post-diagnosis body and attributed these changes to experiencing feelings of depression at the onset of her diagnosis.

At first I thought I was dirty and disgusting, and just knowing that it’s inside of me I struggle a lot with being overweight, so that kind of puts a damper on my self esteem... It depressed me, so... when I am depressed food is my comfort so... when I was diagnosed it was pretty rough. So that’s all I did was eat, eat, eat.

Danielle and Tweety’s stories highlight the emotional and psychological impact of how HIV contributes to the re-construction of relationships with their bodies.

HAART & Body Imaging: Four of the six women interviewed were taking HAART medications. When discussing the effects of HAART it became clear that, for these women, medications transformed their relationships with their bodies. Asha described the HAART transformation of her body as: “Wrinkles... from losing weight... I think it has a lot to do with the meds... It makes you sleepy and kind of makes you fuzzy upstairs. I had some that gave me severe diarrhea, I went off it...”

Elaine saw the HAART-related changes to her body as:

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

Bobby described her body as “going through changes” as she has experienced multiple side effects of HAART medication, that includes both weight loss and weight gain. She shared:

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... 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.

While Ani also experienced side effects of HAART medication, she highlighted the difficult decision women living with HIV are faced with
about whether to adhere to prescribed medications. Ani shared:

*I look tired because your body changes, your meds are strong, and you are very tired all of the time... when you take medication they have a lot of side effects so you have to weigh the side effects... I would say it’s hard. Because sometimes you will get sick from this pill and... always the med has side effects, so really it doesn’t matter what med you take.*

Ani’s story illustrates a conflict between taking medications because they have the capacity to prolong life and experiencing severe side effects that can come with HAART. The effects of HAART were experienced differently by each woman, but these women spoke about ways in which these effects changed the relationship they had with their bodies. Medications did not mean prolonged life exclusively; HAART adherence also meant a life based around a routine of medication, feeling ill, and experiencing changes to their bodies, and how these changes shaped the relationships women living with HIV constructed with their bodies.

**HIV-related Stigma & Body Imaging:** Social and cultural discourses of HIV also played a significant role in the body imaging process through disclosure of HIV+ status and subsequent stigmatizing experiences. For example, following the death of her husband, Ani re-entered the world of dating as a woman living with HIV. She shared:

*To get a relationship it’s hard because you have to tell your partner that you’re HIV... when you meet somebody and you don’t know the person and then... 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 with a story Asha 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... Nobody wants to have sex with you.*

Asha’s story illustrates the cultural narrative of HIV and the body that includes a dichotomization of cleanliness as having an HIV-negative status and dirtiness as living with HIV. The psychological impact of this dichotomy is found in identity formation as having HIV+ status, and sexuality as it pertained to positive interactions with romantic partners.
Bobby shared her experience of approaching intimate relationships as an HIV+ woman who experiences complicated relationship with her body:

> What are you going to do now? You can’t have sex because you’re HIV+; who’s going to want you? I just feel like my body is so messed up and… I wish I had a boyfriend when I was infected or a husband when I found out, then I would already have someone.

HIV-related stigma was described as a difficult experience in constructing meaningful and intimate relationships, as well as in the construction of meaningful relationships with women’s bodies.

**REFLECTIONS & DISCUSSION**

Overall, the stories women shared emphasizes unique challenges women living with HIV must face when constructing a relationship with their bodies, while also illustrating their body imaging experiences pre-diagnosis. Women expressed concern about being big or fat, which Bartky (2010) describes as the ‘tyranny of slenderness’ within the sexist model of female beauty in Western culture. This tyranny is rooted in misogynistic ideas and inequality (Brown, 1985; Davis, 1997; Young, 2005). Although a misogynistic discourse was identified, women still identified ‘skinny’ as a personal ideal, thus bowing to the attainment of the culturally mediated beauty ideal. No story spoke of active resistance to the inequality of this discourse. This observation is congruent with literature that suggests that the time invested for female beauty attainment often deters women from actively resisting the sexism present in the culturally produced models for female beauty (Hesse-Biber, 1996; Hesse-Biber et al. 2004). Consequently, a tension was present in stories in which women struggled to voice frustration with the dominant model of female beauty, but also felt constrained by the model.

Stories shared by women changed as conversations began to include life with HIV. Women’s relationships with their bodies post-HIV diagnosis were centered on themes of physical changes, medication, and experiences of HIV-related stigma. Women living with HIV experience challenging relationships with their bodies just like HIV-negative women do, in addition to experiencing challenges related to the emotional and physical impact of living with HIV. Women shared stories of HAART’s severe side effects as described in literature (Lichtenstein et al., 2001; Carr et al., 2000; Thiebaut et al., 2000; Heath et al., 2001; Persson, 2004), and described how these side effects have come to inform the relationship they have constructed with their bodies. The model of health from which the use of medication develops, focuses on extended life as the goal, while the discourse of female beauty does not encourage
incurring these physical changes. In taking medication, these women experienced nausea each day, weight gain and/or loss, and other changes to their lifestyles and body. Through the experience of severe side effects, medicine truly shaped the lives of women taking HAART in how they felt about their bodies and in their quality of life.

Within stories of constructing relationships with their bodies while living with HIV, conversations emerged that addressed how body imaging intersects with HIV-related stigma. The pressure to disclose of the HIV+ status and the subsequent reaction from others shaped women’s feelings of their bodies. The experience of HIV-related stigma emerged in moments of disclosure when women experienced negative reactions from romantic others. Women described themselves as ‘dirty’ or ‘messed up’, and spoke of their bodies as undeserving of a relationship. While the identification and description of their bodies in such negative terms was alarming, literature suggests this self-labeling could be directly related to the internalization of cultural discourse of HIV+ status, which presents yet another challenge to the construction of a satisfying relationship with their bodies (Gorna, 1996; Lekas et al., 2006; Patton, 1994; Siegel & Lekas, 2002).

Like women who are not living with HIV, women living with HIV experience challenging relationships with their bodies. However, the impact of being diagnosed with HIV, the side effects of medication, and HIV-related stigma result in unique challenges for HIV+ women in the construction of a relationship with their bodies.

**IMPLICATIONS FOR RESEARCH & PRACTICE**

The intersection of gender, HIV+ status, stigma, and body image form an important domain of practice for social workers, counselors, and social service providers. Feminist, postmodern and peer-based counseling are promoted as opportunities for practitioners to provide empowering and non-silencing care. Feminist and postmodern practice can challenge oppression within the therapy room, but also within personal, social and cultural domains by making therapy a political, deconstructive and de-pathologizing activity (Besley, 2002; Brown, 1994; Dietz, 2000; Sands & Nucchio, 1992; White & Epston, 1990). An alternative solution to social service care is for peer support to occur in which an HIV+ individual shares her own experiences and stories with another HIV+ 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+ community (Hughes-d’Aeth, 2002; Molassiotis et al., 2002).
From a research perspective, the implications for future study ismultitudinous. First, the quality of findings, that is the intense stories and personal meanings shared, suggests that this is an important topic for women who are living with HIV and that narrative methodology is a useful tool to explore this topic. When asked just two questions, each woman provided rich stories that illustrated the relevance of this topic in their lives. The women who participated in this study had strong voices, but I fear, if not given an adequate space, they could have been easily silenced by rigid questioning and standardized assessments. Second, it is crucial that researchers consider the power they hold over marginalized populations (Letherby, 2003), and to remain aware of how this power can emerge within the research process. Narrative interviewing was an ideal research methodology because it aligned with the feminist and postmodern basis of the study while also providing increased visibility for those participating in the study. Future research with HIV+ women should include space for open dialogue and participant empowerment. Researchers have a lot to learn from women living with HIV and should continue to create academic space for this learning.

CONCLUSIONS

This study explored the socio-cultural, medical and individual forces that affect how women construct relationships with their bodies and how women find new meaning in their personal identity following an HIV+ diagnosis. The research suggests discourses of female beauty affect women living with HIV as it does women who are not living with HIV. With the onset of HIV diagnosis, women experience their bodies amid new and complicated feelings brought on by HIV related physical changes to the body and social stigmatization. Stories can be a means of speaking to emotions, struggles and challenges related to HIV and body imaging that have previously been ignored or silenced. It is my hope that this research 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 female beauty and HIV though further research.

REFERENCES


