ARTICLES

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Disciplining Bodies, Desires and Subjectivities: Sexuality and HIV-Positive Women

Very little is known about the sexuality of women who are living with HIV, outside the context of risk prevention and education. Available research in the first-world context shows that, although most women continue to be sexually active following diagnosis, decreased sexual functioning is very common and more prevalent than among HIV-positive men. The present multi-site Canadian study is concerned with the ways in which women's sexuality is transformed by the experience of living with HIV. Semi-structured interviews with 20 women were analysed using thematic decomposition, an analytic technique that combines discursive approaches with thematic analysis. The women in this study construct HIV as inhibiting in relation to sexuality. A predominant discourse of disciplining bodies, desires and subjectivities emerges, which centers on the restrictions imposed by an HIV-positive diagnosis. The following discursive constructions, in particular, emerge from the women's accounts: diminished spontaneity, foreclosed (provisional) sexual freedom, foreclosed power, foreclosed flirtation, inciting violence, (un)natural sex, responsibility imperatives, muted/mutated sexuality, and diminished intimacy. The women's predominant positioning within AIDS discourses as conduits of transmission, the relative neglect of women's psychological and sexual health concerns in both research and public health agendas, and women's relatively anomalous standing in AIDS communities imposes limits on bodies, lives, and subjectivities. These are reflected in these women's accounts, wherein a focus on protecting others frequently impedes access to fulfilling (and safe) sexual and emotional relationships.

Key Words: *discourse, HIV, intimacy, power, protection, spontaneity, responsibility, risk*

> That probably was really the *only* thing that was lacking in my life, actual physical sexual activity. . . . Through a lot of tears, a lot of soul searching, you know, it's really hard to be 37 and come to terms with the sexual part of your life being over. But I was just, I think I was determined that it was going to be over. . . . And then sort of after the first year or year and a half of grieving, it just didn't

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> seem that important to me. My life was very full and very happy. And I just, I'm not sure how I decided I was going to live without sex. I don't know if I could tell you what the process was or what kinds of things I thought about. But I think I did go through a mourning period. (Janet)

INTRODUCTION

Very little is known about the sexual lives of HIV-positive women, outside the context of risk prevention and education (e.g. Semple et al., 2002; Simoni et al., 2000; Wilson et al., 2004; see also Logan et al., 2002 for a review). The predominant focus in these studies is on factors that promote or preclude the use of safer sexual practices. Research efforts that consider the impact of HIV on women's sexual functioning are much rarer (e.g. Bova and Durante, 2003; Catalan et al., 1996; Denis and Hong, 2003). Even more rare are in-depth explorations of the ways in which women's sexual and relational lives are transformed by an HIV-positive diagnosis (e.g. Crawford et al., 1997; Lather and Smithies, 1997; Squire, 2003).[1] This is notable given the steadily increasing numbers of HIV-infected women worldwide, with nearly 50 percent of the world's current HIV/AIDS population comprised of women (UNAIDS Epidemic Update, 2004). In Canada,[2] the proportion of women who tested positive has risen from 12 percent during the 1985–97 period, to 25 percent of all adult positive test reports during the period from 2001 to the first half of 2003 (Health Canada, 2003b). Young women are disproportionately affected, with the highest percentage of infected women being in the 20 to 29 age group (32.7%) and the 30 to 39 age group (35.9%) (Health Canada, 2003b).

Evidence about disruptions imposed by a seropositive diagnosis in the first-world context is mixed and comparisons among studies are complicated by sample heterogeneity across and within studies.[3] Some research suggests that for most women, the continuation or resumption of 'normal' sexual activity is the rule, rather than the exception (e.g. Bova and Durante, 2003; Cranson and Caron, 1998; Hankins et al., 1997; Simoni et al., 2000). At the same time, reports of decreased sexual functioning are also very common (e.g. Brown et al., 1995; Catalan et al., 1996; Denis and Hong, 2003; Grierson et al., 2000) and more prevalent than among HIV-positive men (Newshan et al., 1998). The predominant focus in such research is on sexual dysfunction, with hypoactive 'sexual disorder' cited as a frequent complaint.

A recent study examining sexual functioning among HIV-infected women (Bova and Durante, 2003) found that 90 percent of 101 mostly heterosexual (93%) HIV-positive women reported being sexually active following their diagnosis, and the quality of sexual activity was reported to have either remained the same (31%) or to have improved (21%) in approximately half the respondents. When these preliminary findings were first reported at the National Conference on Women and HIV/AIDS in Los Angeles in 1999, a crowded room of HIV-

positive women expressed bewilderment and anger at this apparently rosy picture (Kahn, 2000). The following comment encapsulates this disjuncture between research findings and the intractable 'intricacies of real life stories that occur behind closed doors' (Kahn, 2000: 2): 'I feel confused by the data. They're reporting that people's behaviors didn't change. And that is not the case!' Such discrepancies echo other publications by positive women themselves, usually in the form of personal testimonials in newsletters and edited collections or needs assessments (e.g. Forrest, 1998; O'Sullivan and Thomson, 1992; Positively Women, 1994; Rudd and Taylor, 1992).

In a study that focused on safer sex practices among 230 heterosexually active women (Simoni et al., 2000), 45 percent reported having been sexually active within the preceding 90 days. No information, however, was provided about levels of sexual or relationship satisfaction. A controlled study of 49 seropositive women and 43 seronegative women (Catalan et al., 1996) found that 64 percent of the former group were not in a sexual relationship, whereas only 36 percent of the latter group were not in a relationship. HIV was cited as the key reason for the relationship status by 50 percent of those seropositive women who were not in a relationship. Sexual dysfunctions, including vaginismus, dyspareunia and loss of interest, were also significantly more common among seropositive women than seronegative women.

A recent controlled study of 43 HIV-positive and 73 HIV-negative women (Denis and Hong, 2003) relied on a multidimensional measure of sexual functioning among women to examine such aspects as sexual interest, orgasmic capacity, sexual satisfaction, sexual problems and relationship satisfaction. Compared to HIV-negative women, HIV-positive women scored significantly lower on all measures of sexual functioning, except masturbation frequency and satisfaction. A similarly complex picture was provided by an earlier Montreal study of 161 HIV-positive women (Hankins et al., 1997), which found that 44 percent were sexually active one month post diagnosis and 68 percent resumed sexual activity within a median of four months (range of 1 to 96 months). Eighty percent of this sample was sexually active in the six months preceding the diagnosis. Eighty-four percent of those who resumed sexual activity also reported undergoing a sexual adjustment period (median time 8.5 months). Sexual satisfaction was also rated as low by 57 percent of women in the adjustment period and 32 percent in the current month. Notably, 53 percent of women reported still being in the adjustment period.

In response to The Health and Well-being of People with HIV/AIDS in Australia survey (Grierson et. al., 2000), nearly 60 percent of the 89 women who completed the survey reported being in a partnered relationship and nearly 50 percent were sexually active. Notably, concerns about possible loss of physical and sexual appeal and limitations regarding sexual activity options were commonly cited sources of anxiety and confusion. Questions about the viability and desirability of sexual activity following diagnosis were also very common.

Only a few studies have focused specifically on the ways in which women (and

in some of this research also men) negotiate sexual relationships following an HIV-positive diagnosis. At the conclusion of the 10-year California Partner Study (Padian et al., 1997), which examined the management of HIV and risk within the relationships of HIV-discordant couples, a qualitative component focused on sexuality in the lives of 15 women and 13 men who were in HIV sero-discordant couples (van der Straten et al., 1998). The findings revealed that differing HIV status often resulted in feelings of alienation within the relationship. Despite the fact that most of the participants had been in long-term relationships, many, including seropositive women, experienced HIV as a loss or diminishment of their sexuality. Negotiating multilayered social and internalized stigmas resulted in complex and conflictual psychological and physiological effects on sexuality. Among the central themes were: difficulties in communication about sex; concerns regarding disclosure of HIV status to sexual partners; the burdens of safer sex; loss of desire; and being perceived as sexually invisible.

Crawford et al. (1997) interviewed 27 HIV-positive Australian women about issues of disclosure to sexual partners. Disclosure of HIV status in both ongoing and new sexual relationships was described as being very difficult in all cases. Among the barriers to disclosure were: being counselled against disclosure (for women who acquired HIV medically); feelings of guilt, shame and contamination (for women who acquired, or were presumed to have, HIV sexually); and feeling deviant, socially threatening, and dangerous. Contradictory discourses that, on the one hand, position the 'average' woman as nurturing and responsible, and on the other hand, position a positive woman as 'dirty, diseased and irresponsible', pose great problems for disclosure. Although the authors stated that 'many' of the women in the study eventually formed new relationships, it is not clear how those relationships were formed or whether the women were satisfied with the quality of the new sexual relationships.

Lather and Smithies (1997) conducted individual and group interviews with 25 HIV-positive women over a two-year span; they returned for subsequent interviews and the women's input on the final manuscript several times over the next few years. This research is unique in its emphasis on the joint analysis and authorship of the final document by both the researchers and the interviewed women. The final product is both conceptually and visually multilayered, alternately comprising extensive narratives, theoretical and methodological framings, and relevant statistical information. The section on sexual and romantic relationships echoes the predominant themes revealed by some of the existing research. These included the complexities and complications of: practicing safer sex; negotiating disclosure; maintaining confidence as a sexually desirable partner; facing rejection in and out of relationships; the risks of relationship abuse; and externally imposed and internalized stigmatization.

OMISSIONS, FRAGMENTATIONS AND ACCUSATIONS: WOMEN'S PRECARIOUS POSITION WITHIN THE POLITICS OF HIV

Although these studies provide a partial picture, we continue to know very little about how women actually conceptualize or enact their sexuality in the context of living with HIV, beyond enumerative aspects. This gap is particularly problematic since predominant AIDS discourses continue to recapitulate the paradoxical cultural characterizations of 'women as incarnations of sexual danger, biological power and victimhood' (Squire, 1993: 5). Feminist critiques of AIDS discourses in relation to women are numerous (e.g. ACT UP/New York Women and AIDS Book Group, 1990; Corea, 1992; Patton, 1994; Richardson, 1988; Rieder and Ruppelt, 1988; Singer, 1993; Squire, 1993; Weitz, 1993). These have contributed significantly to our understanding of the ways in which AIDS is situated within a broader matrix of multiple and contradictory sociocultural, political, and personal histories and contexts. Feminist psychology, in particular, is uniquely positioned to address the ways in which these social structures and cultural representations frame, fix or fracture identities, subjectivities, and bodies (Squire, 1993). For instance, women may internalize the dominant discourses of AIDS that position them as 'dirty, diseased, and undeserving' (Lawless et al., 1996a), in ways that impact their physical and mental health. Sexuality is central in these configurations, although its prominence is not always evident. In my interview with Darien Taylor,[4] she emphasized this differential status of sexuality in the lives of positive women and men:

> It's quite remarkable how the men, by and large here [AIDS Committee of Toronto], are out, you know, out there fucking a lot, and the women in here are straight women, some lesbians, but most of the straight women who work here are women who don't have a very vibrant, out there, active sex life or sexuality . . . I see a lot of very ghostly, straight women around here. (Darien)

Patton (2004) recently reiterated that right from the start of the epidemic two vacillating 'representational HIV registers' have been evident in relation to women – 'over-representation and disappearance'. On the one hand, women have been '(mis)used' in the project of 'normalization' to propel certain public health messages about transmission routes, risk groups, and to promote other related public health agendas (Gorna, 1997) – that is, in response to the 'nominal queerness' (Patton, 1994) that marked *anyone* diagnosed with HIV, attempts at 'rehabilitating' HIV have focused on stripping it of its queer alliances and re-branding it as a 'heterosexual' disease, an 'equal opportunity virus' that 'does not discriminate' (Gorna, 1997). Women serve as the *vehicle* for the transmission of this message, although women themselves are not well served by it. This 'women–heterosexual' coupling embedded within the 'heterosexual AIDS' discourse 'responds to society's fantasies of what is normal, of the people whose lives are important and about the ways in which a crisis becomes truly critical' (Gorna, 1996: 6). In this way, the demarcation between 'normal' and 'queer' is

preserved, while women remain suspended in the zone of the unknown and unknowable in relation to HIV. As Janet Connors[5] explicitly stated in our interview, questions about the specificity of a 'heterosexual' sexual repertoire in relation to HIV rarely arise, even in a medical context:

> You know, *nobody ever asked us what we did sexually so, you know, nobody really knows how I got it other than sexually*, but nobody has ever, *not even doctors have ever asked specifically what our sexual activity was so . . . people want to make safe easy judgments*, you know, in some ways that's good because I think maybe, in Nova Scotia anyway, it sort of made the heterosexual population think, holy shit, if it was them, then it could be us. You know, maybe we are doing things that are risky, or maybe we have done things that are risky, so, in that way, I think it's been good. *But I think in other ways our being public has increased that sort of judgmental division. We have the good AIDS and the fags have got what they deserved.* (Connors)[6]

The details of the sexual terrain remain simultaneously murky, unquestioned, and over-determined – 'nobody ever asked . . . nobody really knows . . . not even doctors . . . people want to make safe easy judgments'. This conspicuous omission exposes 'heterosexual sex' as an 'ideological construction' (Gorna, 1996) rather than as a descriptive designation or an epidemiologically meaningful category. The 'good AIDS', ascribed to the 'heterosexual population' is juxtaposed against the 'queer AIDS' acquired by those 'who got what they deserved'. In this way, morally and politically charged representations converge seamlessly with 'epidemiological and media nomenclature' (Patton, 1993) to produce social and scientific distortions.[7]

On the other hand, the specific sociocultural, economic, and biological contexts that often render women more vulnerable both to HIV infection and to adverse health and living conditions after diagnosis have been largely ignored in research, education, and policy initiatives (Pequegnat and Stover, 1999; for an extensive review, see Logan et al., 2002). For instance, the experience of violence may be a strong predictor for women of both becoming HIV infected (El-Bassel et al., 1998; for a review, see also Maman et al., 2000) and being unable to adopt safer sex practices following diagnosis (Champion and Shain, 1998; Hogben et al., 2001). Despite attempts at recalibration, 'the effects of AIDS are never equal, and those discourses which attempt to smooth out diversity with a crass rhetoric of equality render the realities of AIDS invisible' (Gorna, 1997: 147). The first cases of HIV/AIDS were detected in men, linked to gay men in particular, and men continue to be disproportionately affected in the industrialized first world (Gorna, 1997). Although 'at a global level, HIV infects the genders equally . . . there is no one pandemic' (Gorna, 1997: 147) – that is, although the percentages of HIV-infected men and women are nearly equal worldwide (UNAIDS Epidemic Update, 2004), the circumstances surrounding transmission and life after diagnosis are frequently radically different for women and men (Ickovics et al., 2001; Kalichman, 2000). Research and policy agendas have been frequently stymied in

the face of these paradoxical messages that ask 'simultaneously for women to be treated as "the same as" and "different than" men' (Patton, 1994: 5).

This disjuncture between epidemiological and social realities persists. Although women are physiologically two to four times more susceptible to becoming infected than are men (UNAIDS Epidemic Update, 2004), women are positioned variously and precariously within this 'economy of blame' (Patton, 1994) as 'victims, virgins, vamps' (Gorna, 1996) and 'vectors' (Patton, 1994).

The primary preoccupation in relation to HIV and women is with protecting those they might infect – babies, men – rendering women's own health status subordinate to those they 'place at risk' (Treichler, 1988; Weitz, 1993). This exemplary phrase is embedded in the leading paragraph of a recent Health Canada *HIV/AIDS Epidemiological Update* (2003b): 'The HIV/AIDS epidemic among women is of particular concern because of the potential for transmission to their infants' (p.1). The worry about women's status as 'vectors of transmission' is barely disguised here, and is positioned as secondary to the apprehension regarding women's health status. This predominant focus on the 'ever-corporeal' status of women as 'containers' of wombs is most prominent in antenatal HIV screening, where the concern for infant HIV prevention overrides concern about women's risks of exposure or provision of information about living with HIV (Gorna, 1997).

Despite their apparent imprecision, epidemiological reports continue to rely on these obdurately misleading categories – 'general heterosexual population', 'heterosexual contact' (Health Canada, 2003b), 'heterosexual exposure category' (Health Canada, 2003a), 'heterosexually acquired' and 'heterosexual intercourse'. In this way, an obfuscatory 'epidemiology of signification' (Treichler, 1988) is perpetuated. Within this significatory matrix, HIV-positive women's sexuality is virtually erased, outside the persistent social and empirical preoccupation with women as sources of infection (e.g. the large literature on safer sex practices of seropositive women).

METHODOLOGICAL AND ANALYTIC FRAMEWORK

The purpose of our research was to explore the ways in which women living with HIV (re)construct their sexuality post diagnosis and treatment. Semi-structured audiotaped interviews were conducted with 20 women in Ontario and Nova Scotia, from 1994 to 1998. The interviews, conducted by the first author, were part of a larger project on identity renegotiation and disclosure in the lives of HIV-positive women. Most interviews were conducted in the women's homes; several were done in HIV organizations and other public locations (e.g. coffee shops). The interview schedule was sufficiently broad to facilitate an unfolding of individual stories, but was guided by a central question concerning the impact of HIV on sexuality (see the 'Finding and Discussion' section later). All interviews were done individually and each lasted an average of 2.5 hours, ranging

from 1.5 to 6 hours (two separate sessions were needed in a few cases). Participants were recruited via contact with a variety of groups: HIV organizations, hospitals, primary-care physicians, and health clinics. Interviews were transcribed verbatim, using standard grammatical convention to enhance readability and clarity; speech features such as intonations or pauses were not highlighted (see Malson, 1998). Socio-demographic and medical characteristics are summarized in Table 1.[8]

The analysis of the interview material was guided by the following focal question: How has the experience of becoming HIV-positive affected women's sexuality? Sexuality is construed broadly as referring to both physical functioning and psychological enactments. The prompts included questions about relationships, disclosure to new partners, sexual functioning, and desire. Informed by these central questions, thematic decomposition (Stenner, 1993; Woollett et al., 1998) was adopted to explicate the dominant themes. This analytic technique comprises discursive approaches and thematic analysis and is situated within a broader discursive framework (Potter and Wetherell, 1987), which views meanings as socially constituted through linguistic and other signifying practices (Burman and Parker, 1993; Burr, 1995; Parker, 1992).

The term 'theme' here designates coherent patterns identified in participants' accounts (both within and across transcripts) (Stenner, 1993). Discourse is defined in the Foucauldian sense, referring not only to language (i.e. speech, text, signs) but also to regulated social practices that 'systematically form the objects of which they speak' (Foucault, 1972: 49). In this sense, discourses are fundamentally productive of realities (e.g. objects, social institutions, individual subjectivities and 'subjects') and they have a material dimension: they constitute objects, subjects, bodies, and individual and social identities (Prior, 1989). For example, arguably gender norms regulate the 'discursive field' within which female sexuality (in the context of illness *or* health) is constructed. Therefore, women living with HIV constitute their specific (sexualized and gendered) diagnostic and treatment realities within, and against, this discursive backdrop. In this way, 'although participants echo similar "themes," these can be understood as being negotiated within a broader "discursive field," which both produces individual and social meanings and relays meaning through culture' (Bower et al., 2002: 30). Discourse analysis thus defined does not treat participants' linguistic productions as reflecting or unmasking an unmediated reality but rather as actively constituting particular 'versions of reality' (Potter and Wetherell, 1987), which are reified within particular 'regimes of truth' (Foucault, 1972). Available discursive possibilities are simultaneously shaped by, and formulated in resistance to, the inexorable imbrication of knowledge and power (Foucault, 1995). Thus, our analysis is directed at the discursive resources that are employed by the women within each of the emergent themes, rather than extracting some 'putative reality' anterior to discourse (Malson et al., 2002).

TABLE 1
Socio-demographic and Medical Characteristics

Age	M	(SD)
(R = 25–57)	37.55	(8.32)
Partner Status	n	(%)
Single	3	(15)
Partnered	12	(60)
On–off partner	2	(10)
Widowed	3	(15)
Education	n	(%)
Primary	9	(45)
Secondary	8	(40)
Post-secondary	3	(15)
Ethno-cultural background	n	(%)
Caucasian	18	(90)
First Nations	1	(5)
East Indian/Caribbean African	1	(5)
Self-identified sexual orientation	n	(%)
Heterosexual	19	(95)
Lesbian	1	(5)
Employment	n	(%)
Full-time	2	(10)
Part-time	2	(10)
Unemployed	6	(30)
Student	1	(5)
Disability leave	9	(45)
Years since diagnosis*	M	(SD)
(R = 3–9)	4.92	(1.93)
Time since infection*	M	(SD)
(R = 3–15)	9.83	(4.02)
Unknown in one case		
Symptom status**	n	(%)
Asymptomatic	3	(15)
Minimally/moderately symptomatic	13	(65)
AIDS	3	(15)
Mode of transmission	n	(%)
Sexual contact	13	(65)
IV-drug use	4	(20)
Blood transfusion	3	(15)

* These data are only available for 13 women.
** Two of the women began to experience the first opportunistic infections within two months of the interview and one died within several months of the interview.

FINDINGS AND DISCUSSION

The women in this study construct HIV as inhibiting in relation to sexuality. A predominant discourse of *disciplining bodies, desires, and subjectivities* emerges that centers on the restrictions imposed by an HIV-positive diagnosis. The following discursive constructions, in particular, emerge from the women's accounts: diminished spontaneity, foreclosed (provisional) sexual freedom, foreclosed power, foreclosed flirtation, inciting violence, (un)natural sex, responsibility imperatives, muted/mutated sexuality, and diminished intimacy. The self-regulatory imperatives in these constructions are underpinned by a scaffolding of gendered asymmetries that permeate dominant discourses on HIV. That is, women's predominant positioning within AIDS discourses as conduits of transmission (despite women's greater biological vulnerability to contracting HIV), the relative neglect of women's psychological and sexual health concerns in both research and public health agendas, and women's relatively anomalous standing in AIDS communities impose limits on bodies, lives, and subjectivities. These are reflected in these women's accounts, wherein a focus on protecting others frequently impedes access to fulfilling (and safe) sexual and emotional relationships.

Diminished Spontaneity

Nearly all the women spoke about the constraining aspects of practising safer sex. In the following excerpts, the women explicitly equate diminished spontaneity with constrained sexuality:

> My sexual life has changed being HIV because *it's less spontaneous* than it used to be, but it's probably for everybody, the fact of *using condoms*, the fact that my partner is taking extreme care sometimes, so he's less free also. There are things we don't do anymore, *my sexuality has become more constrained*. (Martha)

> It can't be done without discussion . . . . At times I would probably be *less spontaneous* because that whole discussion has to take place. *The sexual activity isn't only my choice anymore*. It's not well, 'I like this and I want to do it and, you know, if you're going to please me then you'll do it' . . . it can't be that kind of relationship anymore. (Phyllis)

Safer-sex educational programs, relying on the 'rational choice' model (Taylor, 1995, 2001), are predicated on the assumption that the primary barrier to the continuance of a 'normal', uninterrupted sexual life in the age of HIV/AIDS is the absence of information and the lack of resources (e.g. no access to condoms). Given adequate information, the logic goes, people will make 'conscientious' choices, which is consistent with the 'ideology of personal responsibility' for health (Lupton et al., 1995; Taylor, 2001). Educational materials emphasize

safety and, relatedly, the liberatory and pleasurable possibilities that such knowledge and resources offer (Lewis, 1998). What is rarely discussed, however, is that many people experience the introduction of safer practices into a sexual repertoire as constraining and mourn the formerly experienced freedom in this arena (e.g. Adam and Sears, 1994; Denis and Hong, 2003; Maticka-Tyndale et al., 2002; van der Straten et al., 1998).

Foreclosed (Provisional) Sexual Freedom

For the women in our study, the limitations imposed by the exigency to adopt safer sexual practices do not merely signal a potentially restricted sexual repertoire, but foreclosure of formerly experienced sexual freedom:

> *I just feel like something's been taken away from me and I can't be as free sexually as I used to be* . . . if it's a new relationship, *then you have to talk about HIV related stuff* . . . I had more control over my sexual life before I got infected. *I can't always – I know this sounds bad, but I wanted to say, I can't always sleep with who I want to* [laughs]. (Patti)

> I'm always aware that I'm no longer just old [name] . . . I have a partner right now . . . but if this relationship with the man I'm with doesn't work out, *I'd love to go out and just party for six months and just fuck the place down*, you know, that kind of promiscuity before you hit 50. I won't be able to do that. *My sex life has been curtailed in that way. I will not sleep with anybody unless he's told and he will understand what I'm saying*, not 'we're drunk and I'm HIV positive and we have sex'. No, it's 'do you know what that means, do you know what the precautions are?' So, it has limited my ability to go out and pick up men, okay? *And it's not like I do this as a constant lifestyle* . . . but . . . (Sarah)

This ubiquitous disclosure imperative, described elsewhere in the literature (e.g. Gurevich et al., 2003; Gurevich et al., 2005; Lather and Smithies, 1997; Squire, 1999) re-emerges continually here in relation to diminished power.[9] Disclosure and power are conjoined. As one woman says in the Lather and Smithies (1997) study:

> Ever since the beginning of time, women have been at the mercy of men and being called disease spreaders and everything and they always have articles in the papers about hookers giving it [HIV] to everybody. Well, if we tell these men that they don't have anything to worry about, they will refuse to wear a condom, and we are all going to be at risk, so we have to go ahead and take the flack from men. (p. 110)

And she is joined by another woman in the group who says: 'Right, we all have to be hookers.' Disclosure is positioned as necessary to protect the health of *all* women, but, in revealing their HIV status, they risk being ascribed the 'hooker' status.

In our study, the contested status of female sexuality emerges in the invocation

of a discourse of (provisional) sexual freedom. In the earlier two excerpts from Patti and Sarah, the discourse of the 'promiscuous woman' vies for position with the discourse of the 'end of the sexual revolution'. The apologetic refrain ('I know this sounds bad'; 'it's not like . . . this is a constant lifestyle') is contiguous with lamentations over the 'right' to sexual exploration ('I can't be as sexually free as I used to be', 'I'd love to . . . just fuck the place down'). These accounts highlight the difficulties of an erotic recalibration of safer sex under conditions of a sexual epidemic, wherein subjects are caught among competing desires and demands (Singer, 1993).

Foreclosed Power

While disclosure of HIV is cited as one of the barriers to resumption of sexual activity in the literature, its regulatory projections are obscured by a nearly exclusive focus on acts, too few of which are designated as dysfunctional. The accounts of the women in our study redraw the power dynamics in sexual interactions as extending beyond decision making about physical acts. Such negotiations are murky enterprises emotionally, intellectually, socially, and corporeally.

> I know for me, *sex is almost a place where you've got kind of power* . . . . And . . . in my moral, ethical universe, I wouldn't feel comfortable not disclosing soon, but *in disclosing soon, I lose my power*. And I don't want to be in a situation where I'm feeling diminished because of HIV. . . . *I think when HIV is there, that really fucks up, not the attraction, but like the enactment of the attraction*. Because you're worried about transmission and I don't want to watch that happen in my lover's eye, or in the way he behaves with me, and *I don't want to watch our relationship change from one of love and sexual attraction to caregiving* . . . . So, that's some of the reason why I don't have sex very often. (Darien)

> So, I think I just decided that I wasn't going to put myself out there. *That was the one risk I was not prepared to take is to be rejected, sexually, because of HIV* . . . by and large I would say the biggest thing that's held me back from pursuing or putting myself out there as a single woman has been HIV. I guess I sort of had thought *it is a huge part of who I define myself as, and I just didn't think I could cope with being rejected because of the HIV because, is that ultimately a rejection of me?* Because that's who I am, you know, I'm not a walking, talking, virus, but I am a woman living with HIV. (Janet)

> Even though they say, 'well tell a partner you've got it', you're so scared to. It's easy to say that but *you're so scared to be rejected, to be alone* you know, it's hard. (Lyn)

Disclosure is framed here as foreclosure of power ('in disclosing too soon I lose my power') and sexual agency ('sexual activity isn't only my choice anymore'). The power is not merely *to do* (or not to do) but also to *inhabit (or inhibit)* some subjectivities. The subject position of 'lover' is (threatened) to be displaced by

the subject position of 'recipient of care-giving' ('I don't want to watch our relationship change from one of love and sexual attraction to care-giving'). Likewise, in disclosing, the subject positions of 'sexually desirable woman' and 'individual' run the risk of being displaced by the subject position of 'a walking, talking, virus,' which is neither sexual nor fully human ('to be rejected, sexually, because of HIV . . . because, is that ultimately a rejection of me?'). The fear of losing an existing partner, who 'accepts' the HIV status, also compelled some of the women in our study to engage in sexual activity more frequently than they desired:

> You know if I don't [have sex], he's going to find somebody else, like that's the old ways, the old, insecurities and stuff, you know, they're there, right. And, yeah*, so a lot of times I feel obligated, you know, out of fear, out of fear that I'm going to lose him* and that, you know, what would I do then? (Denise)

Foreclosed Flirtation

Disclosure and power are coextensive in these accounts in another central way. Playing with erotic possibilities is constructed as constrained here:

> And *maybe I don't really want to sleep with you, maybe I just want to flirt with you* but here I am giving you this information, so again that's a way *that I've limited myself from that activity* . . . . I shouldn't have to feel that way, but the fact is I do. And I'm trying to get past that, that it's okay to flirt, it's okay, you know, it doesn't have to lead into – because it didn't before either. (Janice)

> If you wanna meet somebody, before it was easy to meet somebody. Now no! *It [HIV] held me back*. And even now, when I go with my mother-in-law to her house, there's guys there that, you know, say hello and wanna talk. *And part of me says to myself: 'talk to the person', but then I stop and say to myself: 'what's the use'?* And I'm afraid to tell them. I don't tell them right away. (Lyn)

> When there is no sex and therefore, like kind of all your interactions with, you know, whoever you're sexually attracted to, are really fraught because, okay, *what about flirting, what about, you know, all that, is – it becomes like really highly charged and dangerous and strained*, so I just, I just ended up putting it aside. (Darien)

The women write themselves out of the flirtation script pre-emptively, to avoid disclosure imperatives, possible rejection, and expectations of loaded sexual outcomes. In these accounts, the limits imposed by the disclosure imperative preempts exploration of unpredictable outcomes because there is no time to explore the unfamiliar. The possibilities are indeed 'fraught' because they are always already imagined. The potential is truncated, as disclosure delimits the playing field on many levels. In these accounts, disclosure is configured as installing a premature consequence of the play and rupturing the possibility of transforming these deferrals into creative alternatives.

Inciting Violence

Disclosure and power are also implicated in the potential for danger. In revealing an HIV diagnosis, women also risk inciting violence (Gielen et al., 1997):

> I should have told him right away. See, I didn't want to tell him because *I was afraid I wouldn't be accepted and I was lonely* – my husband had just passed away. *I needed company . . . I put up with a lot of his abuse. Like verbal abuse before the physical came, there was a lot of verbal abuse because of the HIV.* Because part of me in my head, remember on the phone I told you, I kept saying to myself: 'I'm not going to be able to find another man. How much chance? How many people are out there who are walking around with this disease? They [men] would be very nervous, they wouldn't want to go out with me. So, that's what made me come let him come back all the time . . . because I was afraid I wouldn't find nobody else. (Lyn)

HIV-positive women are targets of high rates of sexual and physical violence (Zierler et al., 2000; Gielen et al., 2000). And as Lyn describes above, the capacity to leave dangerous relationships is further diminished by the fear of not finding another partner ('I needed company . . . I put up with a lot of his abuse'). Concerns about finding a partner following an HIV diagnosis are not unfounded, particularly for women who are economically disadvantaged, older, and have less education. A study that focused on the quality of life among women living with HIV found that 44 percent did not currently have a partner (Gielen et al., 2001). This is further complicated by the fact that, as in other studies, these women also reported high rates of child sexual abuse (41%) and adult physical abuse (63%).

(Un)natural Sex

Whereas in the preceding accounts disclosure of an HIV-positive status is framed as inhibiting in relation to psychological and physical enactments of sexuality, a further discourse centers on concerns about the status of 'natural' sexuality. In the following excerpt, Denise constructs the mutual awareness of the HIV status ('you both know') as delimiting the subject position of 'lover'. Although she asserts that the sexual activity itself is barely altered ('it doesn't like get in the way'), the awareness of HIV (signified by the condom) interferes with 'making love' more than it does with having sex ('it does kind of take away from the love-making'):

> It's difficult, you know, cause it does kind of take away from the, you know, *lovemaking I guess. Not just sex*, you know. It doesn't like get in the way, but it's you know, there's that barrier between you, right? It's *not like natural*, I guess. And, and it's, that's a reminder. *When that condom goes on, I have HIV, right? . . . it's the awareness that the condom is there for a frigging reason.* It's not that you don't know or he doesn't know, you know, you both know . . . (Denise)

The public health message of relatively unproblematic, and even 'sexy' safer sex is dismantled here as an illusory, unachievable goal. Reliance on safer sex practices for most of the women in the present study is itself an intransigent reminder of never feeling safe enough. The discourse of 'natural sex' is invoked above to underscore that it is not the physical obstruction itself that is problematic but rather its presence as a signifier. The signified is, of course, not only a disease, but a type of sexuality and subjectivity. The emotional valence associated with equating condomless sex with natural sex is amplified in the context of HIV (Lawless et al., 1996b). Right from the beginning, AIDS emerged as an 'epidemic of signification' (Treichler, 1988) – a disease that does not merely signal a biologically vulnerable body but also a contaminated and culpable body (Patton, 1996; Singer, 1993). An augmented register of deviance and danger exists for HIV-positive women, who are positioned as 'dirty, diseased, and undeserving' (Lawless et al., 1996a), and thus not entitled to sexual pleasure (Lawless et al., 1996b). So, while the use of condoms is viewed as mandatory, it is also menacing in its reminder of an abject status.

Condom use is also 'not neutral' in other ways – in the context of male–female sexual contact, condom use is frequently positioned as signifying an absence of commitment and trust, and associated with casual sexual encounters (Ryan, 2000; Willig, 1994). The 'monogamy narrative' plays a central role in this linkage of 'condomlessness' with 'trust', 'honesty', and 'commitment' (Feldman and Maposhere, 2003; Sobo, 1995). This narrative relies on the belief in mutual trust and fidelity, and thus the absence of condoms signals safety while condom use is positioned as signifying infidelity. As one woman in the present study put it:

> People preach that we should use condoms and, and it's just, we made a choice. It's in the back of my mind that we re-infect each other and stuff like that or give each other different strains or whatever, but you know, we choose to not [use condoms], you know. *As long as we're both committed, we're not going to bring home anything*. (Krista)

Even when condoms are used initially, their discontinuation and delayed application and/or use 'for ejaculation only' (de Visser, 2004) are a routine part of the transition from casual to stable relationships.[10]

Responsibility Imperatives

The exigency to practise safer sex also elicits responsibility imperatives. All but two of the women in this study expressed chronic concern about the possibility of infecting their partner, which resulted in either radically altered sexual practices or abstaining from all sexual contact altogether. This is consistent with research showing that infected women are less likely to put their male partners at risk than vice versa, and a higher rate of sustained condom use is evident when men are at risk of infection (Kamenga et al., 1991). As these accounts suggest, even when sexual activity is resumed, the possibility of risk always lingers:

> So, [I focus] on just doing it *and getting it over with so he doesn't get infected*, I guess. 'Hurry it up, in case that condom breaks or something', you know. (Denise)

> *What risks am I willing to let my partner take*, because sometimes your partner is willing to take risks that you . . . that you know, you can say, 'hey what are you doing here?', and taking responsibility for what is my responsibility and what is your responsibility as an adult and an aware person. (Janice)

> Even though now it's undetectable and I have never passed it on to anybody, you know, I have sex with my partner and it's just, you, . . . *I worry is it going to break*. We have unprotected oral sex, and I went, 'what if you get it?' You know, so there's that part of sexuality that, okay, it doesn't happen very much anymore, you know, but it's always that, that place where you, I question, you know. (Mary)

Women typically accept more active responsibility for negotiating safer sex and are more likely to convince a male partner to use condoms, while men are more likely to be in the position of being encouraged to do so and to dissuade a partner from condom use (Carter et al., 1999). The ultimate decision about condom use relies to a large extent on a male partner's willingness or compliance (Edgley, 2003). Research on HIV-positive women confirms this trend – women consistently report being positioned as the primary custodian in ensuring safer sex practices and men's resistance to condom use is a frequent struggle (Crawford et al., 1997; Lather and Smithies, 1997; Lawless et al., 1996b). This was also borne out in our study:

> We used to have sex without condoms, we started really using condoms more for contraception but I always want to use them, ever since I found out [about the HIV diagnosis]. But at first it was very difficult, it was hard in the beginning, *he didn't even want to, it was hard to get him to use them*, *so it was little by little that, and mostly with me saying that I didn't want to get pregnant*, because that was the way that I started, then we began to use them, . . . then you become accustomed to using them, but there would be times when we wouldn't use them when I became pregnant, but now, *I'm sort of getting to the point where I almost feel like I don't even want to have sex without condoms*. (Nadine)

Muted/Mutated Sexuality

In some cases, concerns about transmission preclude sexual activity altogether. For instance, Marlene struggles a great deal with the loss of sexual intimacy with her husband, but her fear of possibly infecting him prevents her from resuming her former sexual life:

> I think that's [the sexuality], that's probably the biggest effect on my life; *since the diagnosis, we have not had sexual intercourse*. And it's not been by his lack of attention or desire. I can't, in my mind, I'm not looking at kind of *putting him at risk* . . . . (Marlene)

In the case of Diana, her husband's fear of becoming infected has greatly diminished their sexual life. In particular, her own possibilities for pleasure have been negated:

> Well, we no longer have intercourse, that's the basic thing [since the diagnosis]. So, certainly, well *I'm able to love him more than he can love me* is basically what it amounts to. Like he's afraid of, well, as far as touching, there's no – *you should avoid fluids with me*. (Diana)

So, women continue to view themselves as 'vectors of transmission' (Patton, 1994), as do their partners in some cases, although, biologically, women are significantly more vulnerable to HIV infection via heterosexual intercourse than are men (UNAIDS Epidemic Update, 2004). Women's bodies are framed in these accounts, as in those of other studies (Lather and Smithies, 1997; Lawless et al., 1996b), as reservoirs of contaminated fluids, thus rendering any kind of 'erotic welfare' (Singer, 1993) an incessantly precarious proposition:

> Well, it's not safe. You know, *I can't be myself and it's not safe* . . . .Well, we try to make sure that there are no cuts or anything like that because that would be a risk. So, if, if there was a situation like that, we would not have intercourse because of that. (Tara)

And even when 'extreme caution' is taken in sexual practices, questions of dubious safety always linger. As one woman in our study put it: 'But, you know, does the person ever truly feel safe?' (Janice). Current research does not address this difficult question: What does it mean to experience safety for either the seropositive or the seronegative sexual partner? Indicators of sexual act frequency, condom use, disclosure, and relationship status negotiations are central issues but they can also sideline the more intractable issue of whether the experience of sexual safety is ever achievable in the context of HIV.

While some women forego all sexual activity, many others have radically altered their sexual repertoires. The women frame these sexual transformations, in some cases, as bearing little resemblance to their former ways of enacting sexuality, accompanied by changes in the ways they define their sexual selves, in the absence of physically enacting such involvements. These reconfigurations of sexuality are captured in the following excerpts:

> Like the only time I really have sex is when I travel because I'm on my way through, so you sleep with a person a couple of times so that the possibility of transmission is diminished . . . .*What I do now in terms of sex has no similarity to what I used to do, it's like two completely different universes* . . . . I really thought a lot about *what it means to be a sexual person and not be having sex* and how that might be described . . . . *I always say that my sexuality is mutated* . . . . Like I depend a lot on friendships for intimacy and I'm incredibly self-revealing in friendships, to the extent where I think it has sometimes threatened people. But I think that *the intimacy that I get out of that is something that I really need because I don't have sex*. (Darien)

> There are people in my life that I have intimate relationships with that add to that happiness and enjoyment of my life *and I just worked really hard at not being horny anymore, just saying 'okay that part of my life is over'* . . . . I guess I still define myself as a heterosexual woman and I understand that each and every one of us is a sexual being, you know, from the time we're born until we die, and I guess I felt I was a sexual being who was a woman *and if I wasn't going to be a sexual being anymore, then was I a woman? or . . . I think I just didn't know what I was, or who I was. You know, if I wasn't a sexual being anymore, what am I? And what am I going to be? And who am I going to be?* (Janet)

> *I'd love to have an intimate relationship, even, not a sexual* but I mean the intimacy of the trust and the . . . . And I miss dreadfully having no companion, no soul mate. I miss that dreadfully . . . but then in the end, you know, when it comes down to it, then I still don't have somebody to have a cuddle with or . . . . You know, because as I say, *I was very, you know, very sexual . . . . So that part of my life, that sort of intimacy is, is missing . . . . I was a vibrant sexual being until this happened* . . . . It's had tremendous implications. (Kelly)

And even as sexuality and intimacy is conjoined in these accounts, the focus on a radically transformed sense of self as a sexual being is retained. Sex is not positioned here as secondary to intimacy but rather its absence raises critical questions about self-definition ('if I wasn't a sexual being anymore, what am I?'). Not having sex or truncating sexual encounters is configured as effortful, debilitating and as a 'mutation' of previous sexual vibrancy. The problem is not only the lack of sexual contact but the severe limits on the ways in which sex, love, and intimacy can co-exist:

> I've become very passive in that respect, I kind of let stuff go by and just kind of let it float by, I don't engage, don't reach out, don't get it . . . like last year I can remember, at the end of the summer, I'd sort of had this little flirtation. It never actually got into the realm of actual sex, but it sort of hovered there as a possibility for a while. And when I realized that it wasn't going to happen, it was about a month where I was kind of completely, completely devastated, and the thing that came home – that I realized I'd been keeping at bay because it's a very simple thought, but the thing that came home to me very strongly was that I realized in that not happening, that there was a really strong likelihood that I was never going to have sex with somebody who loved me again, and I wept for a month about that. (Darien)

Diminished Intimacy

Diminished erotic possibilities also signalled the loss of intimacy and non-sexual physicality. For women in relationships, the tensions often centered on a persistent longing for a former sexual life and the associated intimacy alternating with the comfort of knowing that their partners were a stable force in their lives. For instance, Diana continues to mourn the loss of sexual intimacy, even as she finds solace in having a permanent partner:

> *I definitely, definitely feel the sense of loss*, you can't help but feel that, you know, *loss of closeness*. And you know, I think whenever you lose that, whenever physically you have to stop that closeness, that it's going to be traumatic. (Diana)

Later she tries to assuage the traumatic impact with the qualifier: 'And that's more than some people get because their partners leave them or whatever . . . .' Similarly, Marlene emphasizes the interconnectedness between emotional and physical intimacy, with sexual contact as the conduit:

> I think it [the lack of sex] *affects the emotional intimacy tremendously*. That's part of the reason that I say, I feel that we've kind of gone on opposite paths . . . because of what we've lost or we're in danger of losing, that intimate involvement, and the caring and the nurturing that you can provide for each other. (Marlene)

In some cases, the loss is anticipatory. For instance, Susan's partner is very resistant to using condoms, which results in their inconsistent use. Given this intermittent practice, she has become much more reluctant to have sex, but is afraid that stopping sex altogether will deprive her of non-sexual physical contact:

> We mostly use condoms but, yeah, we talk about it, but it's another area, a problem, intimacy and sex . . . . But there are issues . . . like in a lot of relationships, I wish that he would be more demonstrative and affectionate and all that. I don't expect it now, but I know a lot of other women feel that way. But you know, you go to more extremes even, *like what if I get sick, then I wouldn't get any kind of affection or physical contact*, you know. (Susan)

These accounts highlight the differential standards applied to male and female sexuality. While male sexuality is positioned as 'omnipresent' (Fishman and Mamo, 2001), spontaneous and driven by unyielding biological impulses (Zilbergeld, 1999), female sexuality is constructed as being more mediated by emotional, cognitive, and social considerations, and frequently needing 'a little push' to activate its full potentiality (Lear, 1995; Roberts et al., 1995). These narratives expose the conflict created by female sexual script imperatives, while simultaneously remaining desirous of more than just 'hugging and touching and so on', as Diana said. Although the women mourn the loss of the emotional intimacy provided by sex, they clearly also miss the physicality of such contact. Because cultural dictates preclude the construction of a coherent and viable 'discourse of desire' for women (Fine, 1988), the focus sometimes leans towards intimacy rather than the sexuality. However, the women also emphasize that the absence of the sexual specifically is problematic, as Marlene does here:

> I can't sit here and say I don't want this to change . . . 'cause *it makes me tremendously sad and I acknowledge how important it is, you know, in our lives, sexual intimacy* . . . it makes me too angry to think that your life is disrupted to that point. (Marlene)

This is also echoed in Sally's account: 'In fact, I probably feel it [desire] more because I probably feel I want to do it [have sex] more because I can't do it.'

CONCLUSION

In this article, we have explored the ways in which HIV-positive women's bodies, subjectivities, and sexualities are constituted in relation to dominant discourses on gender and HIV. In navigating this complex sexual terrain, the discursive constructions that emerge from these women's accounts point to competing imperatives that simultaneously propel and preclude desires for physicality, playfulness, intimacy, safety, and power. The current literature is mixed in its emphasis on the limitations that an HIV diagnosis imposes on women's sexuality. Some studies report very little impact, while others indicate that HIV is disruptive in relation to sexuality. Among the qualitative research that reveals restrictions imposed by HIV (Crawford et al., 1997; Lather and Smithies, 1997; Lawless et al., 1996a, 1996b; van der Straten et al., 1998), there are numerous parallels to our own findings. Discourses pertaining to safer sex constraints, negotiating diminished or (sometimes the even more tricky) persistent sexual desires and disclosure, and struggles with finding a partner and sexual intimacy predominate.

The women's accounts in our study point to an overarching discourse of self-regulation, wherein a focus on responsibility and protecting others delimits physicality and subjectivity. Gender operates in specific ways in these self-regulatory imperatives, impacting both physical enactments and identities. Even when responsibility is less central, the stigmatizing status of HIV ruptures the women's status as sexual subjects in ways that differ from those of HIV-positive men. Adam and Sears (1994) emphasize the similarities among HIV-infected women and men in their examination of how these individuals reconstruct their sexual lives. In particular, they report that following an initial period of withdrawal from sex following a seropositive diagnosis, many individuals resume a satisfying sexual life. Notably, if one examines closely the excerpts cited, those whose sexuality was least adversely affected by HIV were men, and in particular gay men. One of the most obvious differences was the introduction of safer sexual practices into ongoing or new relationships. Notably, Adam and Sears (1994) cautiously note that this 'adjustment was sometimes smoother' (p. 73) for gay male couples who were very familiar with safer sex campaigns. It is significant that in the present study a number of the women who were continuing to abstain from sex or had curtailed their sexual activities had been diagnosed for many years. Many of the women, particularly those active in AIDS organizations, referred to the relatively more active sexual life of gay men as against heterosexual women, and the greater barriers to meeting men for straight women:

> Well, I think the situation is a lot different . . . *if you're an HIV-positive woman in the straight community, like I think that we're still an anomaly*, whereas HIV-positive men in the gay community aren't. I think the gay community is a lot more knowledgeable and a lot more accepting . . . . But in the heterosexual community, that's a community that doesn't feel any particular need to be informed and your likelihood of running across somebody who's HIV-positive is so much lower . . . and *a lot of women don't have a lot of sex*. (Darien)

> I mean a big part of the *AIDS community is the [male] gay community*. And that's really where I've been living is within the gay community. And for as much love and respect and admiration as I have for the vast majority of [them], I'm *still a straight woman*, so I still need to have a pretty big foot in the straight world. It's *things like dating, something I just didn't think about at all*. (Janet)

> I just don't seem to be in circles with men. And *if I go to the [AIDS] Coalition, 99.9 percent are gay men . . . . I can't see that it could ever be quite the same* [*with straight men*] and that would require quite an extraordinary man in my view to get past all the first hurdles of meeting somebody, and then forming a relationship, and then getting to the point of wanting sex, and it's sort of like *there's so many obstacles along the way*. (Kelly)

Relationship context is situated in a complex way here. Women who were not in partnered relationships focused more on the difficulty of meeting a potential sexual and/or relationship partner, with issues of disclosure figuring at the forefront. In contrast, women in ongoing relationships focused more on ongoing sexual and emotional negotiations surrounding HIV. Notably, while a partnered relationship has been described by HIV-positive women as providing psychological protection against feelings of 'otherness' (Jarman et al., 2005), the accounts in our study underscore that this protection does not extend easily into the sexual realm. Although 70 percent of the women in our study were in some kind of partnered relationship, all but one described their sexuality as markedly dissimilar to a pre-HIV status. Importantly, this difference was not positioned as merely an inconvenient alteration of physical practices, but rather as reflecting an altered status as a sexual subject (and object). It is striking that only one woman indicated that her sexual life had remained unchanged, with the exception of having to now 'wear a raincoat' (i.e. condom) during sex (Lynn).

These stories destabilize familiar and comfortable notions about the connections between pleasure, physicality, and desire, compelling us to question the price of 'disciplining pleasures' (Singer, 1993). As Martha said in reading a draft of the written findings, women living with HIV/AIDS are forced to 'construct their own type of sexuality because no appropriate models exist' for conducting a sexual life in this context. Women cannot easily access recognizable images within dominant AIDS discourses (Squire, 1993). In renegotiating their identities as HIV-positive women, the unassimilability of HIV in relation to sexuality remains a central dilemma. These reconfigurations do not submit easily to integration, fraught as sexuality is by conflicting forces and undeniable dangers, and dependent as it is upon complicated connections to material and discursive

practices. Maintaining 'erotic welfare' (Singer, 1993) is a precarious proposition given the ineluctable association between contagion and sexuality. Even two decades into the epidemic, women's concerns are typically ignored in the mainstream public health information campaigns, as Darien asserts here:

> For years people would say, here's information about women and AIDS, and they'd hand me a brochure that would tell you how to put a condom on. It had nothing to do with what I'm interested in . . . I didn't get any information about emotional aspects . . . it was so hard to get information about or to get people to talk to me about me living with HIV. We were completely brainwashed, not just women with AIDS, but everybody providing services to women with AIDS, by a kind of public health transmission agenda. Very sincere people thought what I needed was information about safer sex and that wasn't it at all. (Darien)

There are multiple stories of HIV-positive women's sexuality. The accounts based on our study undoubtedly do not capture the entire landscape. In a recent longitudinal UK study by Squire (2003), the romance genre is used to situate HIV-positive women's sexuality. For these 16 women, the romance stories told by and with other HIV-positive women facilitated broader dialogic conceptualizations of relationships, sexuality, and reproductive issues. Squire (1993) argues that this romance structure permitted 'the women to register desires that more conventional HIV narratives ignore or rationalize' (p. 73), referring specifically to a conventional medical and education focus. She also maintains that 'producing and consuming such situated romances provides us with a way to understand and express, if only as an aside, the ludicrous, abject, impossible desires that conventional discourses of risk, trust and relationships, and conventional romances ignore, or represent only by a floating signifier, a line of dots . . . ' (Squire, 2003: 95).[11] Notably, these stories had varied 'trajectories and ends', with some women recounting 'happy endings', while others related narratives of 'love-in-waiting', and still others had dispensed with such romance quests when specific sociodemographic and psychological conditions changed (e.g. a woman who became unconcerned with romance upon acquiring citizenship status) (Squire, 2003).

No matter the specificities of the stories, we are continually reminded that HIV is often one in a long list of other stressors faced by women. Continuing or resuming 'a satisfying sexual life [is] imbedded in a matrix of issues that have more to do with the socioeconomics of poverty and oppression than with HIV itself' (Bova and Durante, 2003: 81). In the Squire (2003) study, not only were the romance stories inter-spliced with other 'romances' (e.g. searches for self-discovery, social acceptance), even the more apparent and specific 'happy ending' motifs were intermittently ruptured by narratives that reflected dominant gender differentials along social and psychological lines. Specifically, the stories also told of excessive caregiving burdens, disclosure negotiations, communication difficulties, violence, addictions, unemployment, migration, financial constraints, infidelity, and nagging doubts about male partners' motives for remaining in relationships (e.g. sero-concordant status).[12] And the spectre of

guilt, contagion, and death never completely recedes. Similarly, a recently published account based on interviews with 37 HIV-positive women (Ciambrone, 2003) suggests that, as with other research on women's mental and physical health in relation to marriage and long-term relationships with men, the benefits of such relational connections are not always evident. Many women living with HIV continue to juggle multiple caregiving roles (partner, mother, daughter, etc.) and often face emotional and physical abuse that predates or follows their HIV diagnosis. Not surprisingly, sexuality is often situated ambivalently, awkwardly and, at times, dangerously within such broader possibilities and precincts for relationality, physicality, and subjectivity.

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NOTES

1. Although a few studies that focus on men also include women, their numbers are much smaller and a less clear picture of their lives is available. For instance, Maticka-Tyndale et al. (2002) examined 31 men and 4 women; Adam and Sears (1994) reported on 48 men and 12 women.
2. Our study explores the lives of Canadian HIV-positive women; the focus on Canadian statistics is, therefore, relevant in this regard.
3. Results vary considerably depending on the medical and socio-demographic profiles of the participants both within (e.g. HIV-positive compared to HIV-negative women) and across studies. Among the key aspects that contribute to the variability are: health status, injection drug use and substance abuse, physical, psychological and sexual abuse history, and current status.
4. Darien Taylor was one of the study participants and the co-founder, along with Andrea Rudd, of *Voices of Positive Women.* Founded in Toronto, this was the first Canadian organization devoted exclusively to the needs of positive women. It continues to be a non-profit, community-based organization. Ms Taylor was recently (2004) appointed Director of the Canadian AIDS Treatment Information Exchange (CATIE).

5. Janet Connors, a participant in our study, was one of the key contributors to the development of the AIDS Coalition of Nova Scotia.
6. Italics refer to portions of the excerpts that pertain directly to the discursive constructions described.
7. A vivid example of this erasure of the particulars of the (ostensibly) self-evident heterosexuality, even in more progressive and well-intentioned safer sex campaigns, is provided by Lewis's (1998) analysis of three safer sex pamphlets funded by Norwegian Board of Health in 1990. The three brochures appear as a series and target three groups: 'men who have sex with men', 'heterosexually active women and men', and 'women who have sex with women'. Lewis shows that both the textual and visual differences among the three documents depict female sexuality as passive and asexual, and heterosexuality is sanitized in ways that simultaneously neutralize its erotic valence *and* its potential as a source of danger. Twelve pages of sexually detailed text are allocated to the 'men who have sex with men' pamphlet, while heterosexual activity is described within nine pages, and only six pages are needed for sex between women. The disparities among the visual images are even more telling. The men's brochure contains explicitly erotic images of sexual mutuality, pleasure, and agency on the part of the participants (Lewis, 1998). In contrast to these representations of vibrant, joint (and joined) and active male sexuality, the booklet depicting heterosexual activity segments the bodies and pleasures of the sexual pair (Lewis, 1998). Nudity, desire, arousal, and agency are conspicuously absent throughout, particularly in the images of the female participant. These deactivated images of propriety and modesty are paradoxically and awkwardly positioned alongside a 'text that purports to speak of condom use, anal sex, oral sex, masturbation, safe navigations within orgasmic pleasure' (Lewis, 1998: 129). Such absent desires and muted allusions to specific practices make it difficult to imagine and visualize activities that might pose a risk for HIV transmission in the context of 'heterosexual acts'. The booklet intended for women who have sex with women is completely devoid of women's bodies and 'contains virtually no elaboration of graphic details of what lies behind the "named" possible activities . . . . What has been put into circulation is an impoverished text, a negation – by default and blocked visualization – of sexual embodiment' (Lewis, 1998: 130). Notably, identity politics are ignored here: 'The "sex with men" information would be crucially important to have access to here, right in this "lesbian" target text – because "women who have sex with women" and women who are lesbian self-identified are most at risk of infection when they have sex with men' (Lewis, 1998: 130).
8. The women comprised a fairly heterogeneous group in terms of medical and demographic characteristics, with the exception of ethno-cultural status and self-identified sexual orientation. Given the complex issues discussed throughout the article, this is a particularly difficult population to access, which limits sampling heterogeneity; this was also reflected in the length of time taken to complete the project.
9. Incidentally, more seropositive women disclose their status to all sexual partners than do seropositive men (Chervenak and Weiss, 1989; Stempel et al., 1989).
10. Research with female sex workers also confirms that condoms represent 'sex as work', while condomless sex is designated as 'loving sex'. The following quote from a sex worker in one such study succinctly captures this distinction: 'You're having sex with a condom. You're making love without' (Woods, 1996: 132).
11. Another example of attempts to depict the sexuality of HIV-positive women in alter-

nate ways is the recently established online magazine for HIV-positive women entitled *Dentata: A Zine for Chicks with the Package*. This was the brainchild of Susan Forrest, an HIV-positive activist, who wanted to provide a forum for women living with HIV and their partners to discuss issues pertaining to having and enjoying sex, rather than being told 'how to' or 'whether to' have sex by the HIV education and prevention literature and campaigns (Forrest, 1998). The magazine title capitalizes on and attempts to subvert the mythology of the 'vagina dentata', (vagina with teeth), representing the dangerousness of female sexuality and anatomy.

12. Notably, HIV sometimes functioned as a narrative exemptor, allowing women to formulate tolerable understandings of dissatisfying circumstances. Examples included reliance on explanatory narratives that emphasized 'a life lived in defiance of HIV' (Squire, 2003: 88) and the threats to masculinity that an HIV diagnosis confers.

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