

# Women, HIV, and the heterosexual encounter

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Paper presented at

The Pozhet Women's Forum

Claffy Theatre, Sydney Hospital,

24 November 2005

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In this paper, I explore HIV in the context of heterosexual relationships, drawing on stories from the *Straightpoz study*. This study includes both men and women living with HIV heterosexually, but I will focus on the women for the purpose of this forum. I'll say a few things about the study in a moment.

But first I'd like to refer to Corinne Squire (2003) who asks in her provocatively titled article: "Can an HIV-positive woman find true love?" Squire, who did research with positive women in the UK, argued that the women faced the same issues around relationships that most women do; trust, intimacy, sex, compatibility, children, and how and where to meet someone. These issues, however, were all shaped by the presence of HIV in complex ways. Squire goes on to say that because of the stigma of HIV, "a romance told in the context of HIV is, in a sense, a story told *against* HIV", but it is also always a story *about* HIV, as relationships and sex must be negotiated in relation to the virus, not only by the women themselves, but by the men that enter their lives (2003: 79-80).

So, it is also a story about heterosexuality. As I will explore, heterosexuality is powerfully shaped by cultural discourses that constitute gender with particular references to power, sexuality, and responsibility, which poses some specific problems for women with HIV. This is further complicated by HIV being not only stigmatised, but also largely *invisible* among heterosexuals in Australia. It is not woven into language, relationships and awareness in the way it tends to be among gay men. In the heterosexual encounter, HIV is an anomaly; it is unexpected, and people with HIV are often imagined as sexually deviant in some way, or as having no right to a sexual life (Crawford, Lawless & Kippax, 1997; Waldby, Kippax & Crawford 1993a; Lawless, Crawford & Kippax 1996). So, how do women with HIV negotiate relationships and sex in this context?

Before I go on, I'll say a few things about the study. The *Straightpoz study* is a qualitative study with positive heterosexuals and serodiscordant partners in NSW, conducted by the National Centre in HIV Social Research in collaboration with Heterosexual HIV/AIDS Service, NSW. It explores a range of issues, including diagnosis, stigma, disclosure, relationships, sex, children, sociality, and contact with HIV services and other positive people. As far as we know, it is the first study of its kind in Australia.

The study includes 31 participants from a range of socio-economic and cultural backgrounds.<sup>1</sup> Nine of these are positive women between the ages of 24 and 64, with most in their 30s and 40s. They tested HIV-positive between 3 to 19 years ago, with a median of 11 years.<sup>2</sup> Seven women lived in Sydney,<sup>3</sup> one in a regional town, and one recently moved interstate. Four women were employed, one studied, one ran her own business, one was a full time parent, and two received a pension. They had little contact with the broader PLWHA movement, though some attended Pozhet events or the Haven in Blacktown. None were involved with positive women's groups, though several had been in the past. Five women had children, with thirteen children between them (one woman being a mother of six). Three were born post-diagnosis, with one child being HIV-positive. One woman became pregnant shortly after the interview, and another was in the process of trying to conceive.

Relationships were a major issue in most *Straightpoz* interviews. But in comparison to the single men in the study, the women were generally more optimistic and active around relationships, and relationships were something that had figured in one way or another in most of the women's lives post-diagnosis. At the time of diagnosis, eight women were in a relationship. While four women

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<sup>1</sup> Participants were recruited through the *Positive Health* survey (NCHSR), through Pozhet, and through *Talkabout*.

<sup>2</sup> Unprotected heterosexual sex was the most common mode of infection (5), followed by blood transfusion (2), needle sharing (1), and unknown (1, but with heterosexual sex thought to be the most likely mode).

<sup>3</sup> 2 women lived on the north shore, 1 on the northern beaches, 3 in the western suburbs, and 1 in the eastern suburbs.

were infected within that relationship, none expressed resentment towards the men, primarily because all believed their partner had been genuinely unaware of their HIV status. Yet, most of these relationships ended, either due to stresses caused by HIV or due to other reasons. At the time of the interviews, two women were single, three were actively dating, and four were in committed relationships, only one of which pre-dated HIV.<sup>4</sup>

The invisibility of HIV in heterosexual society was evident in reactions to diagnosis. Most women were stunned to learn that they were HIV positive and had little understanding of what this meant for their lives in terms of health, longevity, reproduction and sexuality. Ellen, who tested positive in 1997, said:

When I first got diagnosed, my first thought was I was going to die sort of fairly soon, maybe within a couple of years or something. My second thought was that I would never be able to have sex again. And my third thought was I will never be able to have children. Nine years later I haven't died. I've had sex. And I have a child.

Initially, few women thought they would ever have a sexual relationship again. Internalised stigma was a strong theme, and many struggled with feelings of pollution, shame and undesirability. Even after many years, stigma and fears of infecting someone else posed a major barrier to relationships for two of the women in the study. Meagan and Fiona were among the women who had been positive the longest. Both were diagnosed in the 1980s and spoke of the Grim Reaper ads as highly formative of their attitude to HIV and of themselves as HIV positive women. This is what Meagan said:

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<sup>4</sup> The two women who remained in their relationships were both diagnosed at the same time as their partners. Today, Grace is still with her husband, while Audrey's partner died of AIDS related illness a few years ago and she is now in a new relationship.

Well, the Grim Reaper ad came out and I thought to myself 'I'm never going to run the risk of infecting someone'. Then it became such an ingrown phobia ... I didn't feel comfortable about having a relationship with anybody. Then things settled down a bit and I sort of came more to terms with it. I was no longer – I think 'unclean' would have been the term I would have used to describe myself at the time, or 'infectious' ... [But] I still have the idea that really I am damaged goods ... It's hard-wired into the brain, in the subconscious, if you like. And it's not going anywhere. That's where all my prejudices against myself are still hiding. They're still there.

Counselling and positive women's peer groups gave many the time and support to process their feelings around being HIV-positive. For some, self-acceptance was the key that opened up the possibility of a relationship, as Olivia explained:

I went through a long period, seems like ancient history now, but I remember when I was first diagnosed, I felt so dirty. Like everything about me was, I suppose, unsafe and unclean and my blood was just full of crap. Just the whole thing was very internalised ... For the most part now, I feel loveable. I feel good about myself. I just feel like I've still got a lot to offer and give and that I can be part of a strong, healthy relationship, despite the difficulties, I suppose.

For others, acceptance by a sexual partner helped lessen feelings of stigma and undesirability. Ellen described her first relationship post-diagnosis in this way:

I think it was very lucky for me that he was in my life at the time ... because he was able to accept me for how I was. We had a relationship for about six months. It didn't develop due to other reasons, but we had a sexual relationship, safe sex, and that was really

fantastic for me in the sense that, hey, somebody still wants me, somebody is still willing to touch me, kiss me, whatever. All that stuff. So that was really, really good.

HIV-positivity was not something the women simply “worked through” and then moved on from. Rather, HIV was an ongoing process of negotiation, particularly in the context of relationships. Along with the stigma of HIV, meeting a potential partner presents positive women with several dilemmas which they must attempt to resolve, including: legal requirements to disclose HIV to a sexual partner; contradictions between safe sex discourses and gender role expectations; as well as discourses that emphasise the responsibility of the positive person to protect their sexual partner (Crawford, Lawless and Kippax, 1997: 6-7). These dilemmas were negotiated in different ways in the women’s stories. And this is what I focus on in the rest of the paper.

Firstly, disclosure to a sexual partner was seen as a highly fraught decision. Not only did it bring up the women’s own issues around being HIV-positive, but they also had to be prepared to deal with another person’s reaction. This is how Donna described it:

Certainly when I meet a man, it raises its ugly head, every time, obviously. I have to make those decisions as to whether or not to fess up. That’s had an incredible impact on me ... It’s tricky when you go into a relationship, how you handle it and do you trust them to tell? At what stage do you say you’re HIV positive? At what stage do you say, ‘this is the reason why I want to use precautions’?

Most women were aware of the legal requirement to disclose to a sexual partner, but their ability or willingness to do so was often complicated. Legal requirements to disclose assume “the possibility that everyone can disclose their HIV status at the time of every sexual act” (Worth, Patton & Goldstein 2005: 10). But this assumption disregards the cultural complexities of sex, romance, and gender power relations, and the many valid reasons why individuals do *not* disclose

their status, including stigma, fear of rejection, gossip, and violence: “The very idea of disclosure assumes that sex takes place ... between partners of equal power and with some impetus to speak” (2005: 10).

Disclosure is also complicated by the invisibility of HIV among heterosexuals. How do you reveal the totally unexpected, the unfamiliar, the unthinkable, and then manage people’s ignorance or fear? Women with HIV may themselves be unfamiliar with the process of disclosure, at least initially, because stigma “itself is likely to be an entirely new experience”, so they may have “no role models of disclosure on which to draw” (Crawford, Lawless & Kippax 1997: 11). This was evident in many women’s stories. Zoe, for example, dated a man eight months after testing positive, and did not disclose before they had sex:

We were using protection, but the condom broke, you know, and then I thought “Oh shit, I’ll have to tell him”. So I told him ... and then we’d been around to the doctor and he got some medicine, whatever you have to do. But he was alright after he found out. Like he probably thought maybe I should have told him beforehand, but he was the first person I met, you know, so I didn’t know *how* to tell him.

The difficulty of disclosure was acknowledged by Audrey’s partner Jason who, after they had had sex, found out about her HIV status through gossip in their close-knit cultural community:

I asked her, why didn’t she tell me? She reckons she was thinking that she was going to tell me, but she didn’t know *how* to tell me ... with this kind of sickness it’s pretty hard for a person like herself to tell someone like me, yeah. Like she hasn’t had someone for ten years, but she’s fallen in love with me, and she doesn’t want me to go, and she didn’t know how to tell me. She probably thought I was going to leave her, yeah.

As these two accounts suggest, the *timing* of disclosure to a sexual partner can be a particularly difficult decision to negotiate. The women struggled with the dilemma of whether to tell straight away and risk rejection, or whether to wait and see if the relationship develops into something more serious and *then* disclose, in which case rejection can be devastating because of greater emotional investment. If they wait to disclose, the partner might also get upset or angry that they were not told earlier, especially if sex has already taken place. Or they might feel emotionally deceived.

Trust, as Stephenson (1994) points out, is central to discourses of coupledness. In one sense, for a positive woman, “disclosing her serostatus also means disclosing implicit dishonesty, so that in being honest she is confessing to having been dishonest” (Crawford, Lawless & Kippax, 1997: 10). However, the issue of trust goes both ways. For the women in the study, being able to trust their potential partner was a prerequisite for even contemplating disclosure. Donna explained that unless the relationship appeared to have some long-term prospect, she was not prepared to disclose:

Once I've worked out that, yes, I'd sort of like them to stay around, then I start weighing up the pros and cons. Then I start to try and figure how they will react ... I have to be pretty confident, I'm hedging my bets that I've got more than a fifty-fifty chance that they won't lose the plot or get silly. I have to trust them. I really have to trust them that they won't go public with it.

The women approached the issue of disclosure to sexual partner differently. Olivia, for example, felt it was important to disclose prior to sex, not out legal obligation so much as out of a sense of responsibility, but emphasised the importance of being emotionally prepared:



Like for my own conscience I had to be able to disclose before any sexual relationship occurred. That was just a decision I made. But in order to do that, I really had to feel like I was okay and that there is always hope ... because there's always the possibility of getting the flick very, very hard, very coldly, very quickly. So I had to work on that for some time so that, if it *did* happen, I would be okay and I wouldn't crumble.

Donna, on the other hand, relied on safe sex to counter what she saw as an unreasonable obligation to disclose. She believed it was acceptable *not* to disclose as long as she did not put her sexual partner at risk:

I have dated men that there's no way in the world I'd tell. No way! ... If I've decided I want this man in my life, more than casually, then I will disclose to them that I am positive. Now, have I had sex with them prior to that? Yes, probably. Until such time that I've told them, I've always ensured that there's precautions – which in itself is a pain in the butt.

Relying on safe sex was not an easy option for everyone. The lack of HIV awareness and a safe sex culture among heterosexuals often complicated the matter. As Crawford, Lawless & Kippax point out, because the epidemic has largely been associated with gay men, it means heterosexual men and women are automatically assumed to be HIV-negative. HIV transforms the heterosexual encounter into unfamiliar territory and positive women must renegotiate some of its meanings “and cannot rely on the other participant in the encounter ... to share their understanding” (1997: 7).

The capacity to renegotiate the heterosexual encounter is constrained by safe sex discourse being largely incompatible with cultural meanings and practices of heterosexual sex. Not only is penetrative sex normative, but research continues to identify strong cultural barriers to condom use among heterosexuals, particularly men, including beliefs that condoms are unnatural, that they compromise the pleasure of sex or interfere with romance and trust. The highly gendered nature of heterosexual sex gives women less room to negotiate, as heterosexuality is constituted by two complimentary discourses: one that positions men as uncontrollably sexual, and therefore free from responsibility, and one that positions women as sexually passive and self-sacrificing if there is any resistance on the part of the man to use a condom. Yet, at the same time, because of their passive sexual role, women are expected to take *responsibility* for safe sex. Safe sex, however, tends to be understood as contraception; as protection against pregnancy rather than infection, with the help of technologies that do not “compromise” male sexuality. In this discourse, insisting on a condom positions women as sexually active and therefore dangerous, promiscuous, and possibly diseased (see Moore & Parker Halford 1999; Crawford, Lawless & Kippax 1997; de Visser 2005; Kippax, Crawford & Waldby 1994).

These dynamics were difficult to negotiate for many of the women in the study, and the stress caused by having to make up excuses for insisting on a condom, or for not having sex at all, meant they sometimes felt pressured to either disclose or end the relationship prematurely. In the few situations where the women had unprotected sex without disclosing, there was considerable emotional upheaval and self-blame.

These examples hint at the complex dynamics at play in decisions around disclosure and sex. While some women had developed strategies and rules, others made a decision based on the situation at hand. And others found themselves breaking their own rules in “the heat of the moment”. The lack of hard and fast rules for disclosing to sexual partners, along with the fact that

heterosexual sex is relational and tends to be negotiated from quite different positions of power, made each particular situation a complex experience, rather than a matter of rational choice and routine.

Whatever the approach, the discourse of responsibility was often implicit in the women's accounts of meeting a new partner, whether in relation to disclosure or safe sex. Many prepared carefully for disclosure, ensuring that the time and space were safe and appropriate. They made sure they had plenty of HIV-related information at hand, they took on the role of educator, and they prepared themselves emotionally, not only because of possible rejection, but because the partner might react with a range of emotions or questions and be in need of emotional support.

Once they entered a relationship, issues of sex and responsibility often became more complicated. Responsibility is not only gendered, but discourses of HIV often emphasise the responsibility of the positive person to protect their sexual partner, which robs the HIV-negative partner of responsible agency in sexual decision-making. However, taking on responsibility was often driven by profound fear of infecting a partner, leaving little room for negotiation. Olivia, who recently married, made it a rule to always use condoms, which she saw as necessary to, as she put it, "protect my husband", a decision that was both a source of comfort and frustration:

It's hard to be a romantic *and* HIV-positive, because I suppose I have always envisaged myself, you know, to get married and have that intimacy, having sex with your partner and having children naturally and all that kind of stuff. Well, in a sense that might be available to me, but it wouldn't come without a large amount of guilt, and a large amount of worry, and it's too hard, I don't want to do that, and I don't want to put my husband in that position, so that's something, I guess, I had to give up.

Some women resisted discourses of responsibility and reinterpreted safe sex contrary to common understandings. In Donna's previous sixteen year relationship, unprotected sex had been the norm. She emphasised the safety ensured by her undetectable viral load and by the practice of "gentle" sex and sexual abstinence during menstruation. She also emphasised that it was her partner who *chose* to have unprotected sex; that the decision was *his*, not hers. Of her current partner she said:

He too has elected not to have protected sex because of my good health ... I'm surprised, but that's his decision ... So it's a wonderful thing for me to have that acceptance ... It's wonderful to know that not everybody is hysterical about the disease.

By and large, sexual decision-making was something the women either took responsibility for, or handed over to their partner after disclosing and providing them with relevant information. Rarely was sexual practice spoken of as a mutually negotiated responsibility. In some relationships, sex was presented as something that simply "happened" (cf van der Straten, et al 1998). One couple I interviewed said they had mainly unprotected sex and only occasionally used a condom. Neither could articulate how or why they made these choices and neither spoke of it as an "issue". He said:

We've had unprotected sex since we've been together. There have been a couple of times when we've had protected sex but, yeah, we've had unprotected sex, oh well, even today [laughs] ... we've been to the doctor's, but that was a while back. I hear what [the doctor]'s saying, but I don't really take it in. I just think 'Oh, so what?' ... It doesn't really matter.

The absence of a negotiated approach to sex hints at the contingencies of love and lust. But it also hints at the cultural construction of heterosexuality as “natural”, as beyond change, unlike gay sex which has been shaped by history and HIV as a negotiated practice open to mutual reinvention (Waldby, Kippax & Crawford 1993). What this also signals, perhaps, is the absence of a language around not only sex, but around HIV among heterosexuals. Many stories were suggestive of this absence in general. For example, some women found it difficult to talk to their partners about their fears of infecting them or about the underlying stress of their partner’s essentially *unknown* serostatus most of the time. Conversely, one male partner, Simon, talked at length about how he felt his partner was not able to communicate her feelings around being positive to him. He was concerned that her “holding back”, as he put it, made her upset, and made it more difficult for him to understand and support her. In some relationships, HIV wasn’t discussed at all. As Jason said:

We go on with life like there’s nothing wrong. I never bring it up. I don’t know why I haven’t brought it up. It’s never an issue at all ... no, we never talk about it ... there’s too much going on in life, because this is like minor ... I don’t know about her. It might be a big thing for her. But for me, because I love her, I don’t really give a damn.

Some women welcomed the fact that their partner did not make an issue of HIV. They spoke of this as liberating, to be treated as “normal”, and saw it as a sign of their partner’s unconditional acceptance, while others recognised that their partners may simply be incapable of understanding. Yet, for others, silence around HIV meant they were forced to carry the responsibility alone, or it was seen as a sign of their partner’s denial of HIV, his refusal to engage with it, even after many years, like a hidden stigma that could simply be wished away. Donna described this invisibility of the virus in her previous relationship and how acceptance can be conditional and not necessarily synonymous with support:

My last partner, my sixteen year partner, didn't want to know anything. Never once came with me to a doctor's appointment, he was not supportive in that respect. He was very happy to stay with me, to live with me, providing the virus didn't raise its ugly head and wasn't in his face. So he was accepting – but didn't want to know about it. If I got sick, *he* went to bed. He didn't react very well at all to it, which was a burden for me. In actual fact, I would prefer to have been on my own than to, *really*, carry *him* in the relationship.

It is noteworthy that several women emphasised a lack of support and resources for male partners (cf van der Straten et al 1998). This was evident in the story of Ruby who recently met a man who had great difficulties dealing with her HIV. Their mutual affection was strong and although he wanted to get married, he refused to have sex, terrified he would get infected. He was also fearful of how his family would react if he told them, finding it difficult to accept that he didn't necessarily *have* to tell them. Ruby tried to support him by giving him information and going to counselling together, but was unsure how it was going to end unless his attitude changed. She was prepared to wait, but not forever as she felt she was continually called upon to support *his* needs at the expense of her own, including her sexual needs, her wish to start a family, and her desire to get on with her life.

I've said "look, you know, I'm prepared to wait", and I said "but I can't wait for years". It's like "okay, I'm okay with it at the moment, you're okay, but I think at some stage, I'll feel that, you know, I want to make love to you", do you know what I mean? I think that's just a natural thing ... He sort of keeps saying "What will happen if I don't, like if I can't?" And I said "I don't know. I'm going to have to make that decision". And he's like "No, we can't separate". And that's what I'm finding very hard at the moment ... I'm trying to

understand *his* side of it as well. But then, at what point do I sacrifice *my* wants and needs? Yeah, it's sort of weighing it all up.

Ruby said that requests to a health service that they be put in contact with couples in a similar situation were unsuccessful, adding that, “we’ve found that that support has been quite hard to get hold of”. In the *Straightpoz study*, male partners had minimal contact with HIV services and support groups. Counselling was rare and HIV testing was sporadic. Olivia pointed out that it is hard to give unbiased information when you are *in* the relationship, and it places too much responsibility on the positive partner. She stressed that it is important that a partner gets information about HIV, safe sex and testing from a professional, so they can take an active, informed part in decision-making. Thus, appropriate support and resources for male partners were seen as essential also to the support of women with HIV.

To conclude, most of the women in the study were sexually active, either presently or in the recent past and several had developed loving and supportive relationships post-diagnosis. A relationship without sex was not acceptable to most, and several women had ended relationships where sex was either absent or too problematic because of a partner’s fears. In doing so, they resisted not only heterosexual discourses that deny women an active desire, but also the stigma and desexualisation of people with HIV in general. At the time of the interviews, two women had resigned themselves to not having a sexual relationship, a decision partly related to barriers posed by both external and internalised HIV stigma, and partly related to other circumstances.<sup>5</sup>

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<sup>5</sup> Both women lived fairly isolated, solitary lives with few social opportunities to meet someone, a situation that was compounded by other conditions, such as depression, lipodystrophy, and agoraphobia. Meagan said she was reluctant to pursue a sexual relationship because she feared a rejection would “destroy” her and trigger her depression. “It’s easier not to have a partner”, she concluded. Similarly, Fiona remarked that HIV has had “a massive impact” on her life, “because it means I can’t have a man in my life”. She said: “I could not, would not take the risk of giving someone what I have. I’d be too frightened. I couldn’t have sex with a person. I couldn’t enjoy it if I did, I’d be too freaked out, you know”. A third woman, Grace, also abstained from sex, but for completely different reasons. The poor health of her husband, who was also HIV positive, made sex too difficult, but they had found other ways to show affection and love.

Although it was never seen as an easy thing to do, few women had had any bad experiences in relation to disclosing to a sexual partner. This may partly be because they tended to carefully prepare emotionally and practically for disclosure, and to be careful about the men who they chose to disclose to. While good experiences of disclosure were reassuring to the women, their stories also suggest that testing HIV-positive does not necessarily involve a linear progression from initial despair to gradually regained confidence and a coherent reconstruction of identity and meaning. As they dated, entered into a relationship, broke up, or changed partners, issues around stigma, disclosure, sex, trust, and intimacy had to be repeatedly negotiated and renegotiated. As Corinne Squire writes: even when HIV is not life-threatening, it is *life-shaping* in that romance, love and sex are always affected by the virus and cannot be negotiated in its absence (2003: 80).

For the women in the study, *how* HIV shaped relationships and sex was in turn shaped by the stigma of HIV and by cultural discourses of heterosexuality. For many, it was in the context of heterosexual romance and sex that they were infected in the first place. Yet, in HIV research, prevention and safe sex education campaigns, male heterosexuality is often excluded, invisible or unproblematised, reinforcing the notion that it is women who are responsible for what happens in the heterosexual encounter, a cultural pattern identified by many researchers (Waldby, Kippax & Crawford 1993; Wilton 1997; Richardson 1996: 173; Waldby 1996). I would add that the men who enter the lives of women with HIV are similarly invisible, and little is known about how HIV and stigma shape *their* lives, including their sexual practice, or what some of the barriers might be in terms of their accessing services and support. These are some of the issues we hope to explore further in the *Straightpoz study*.



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