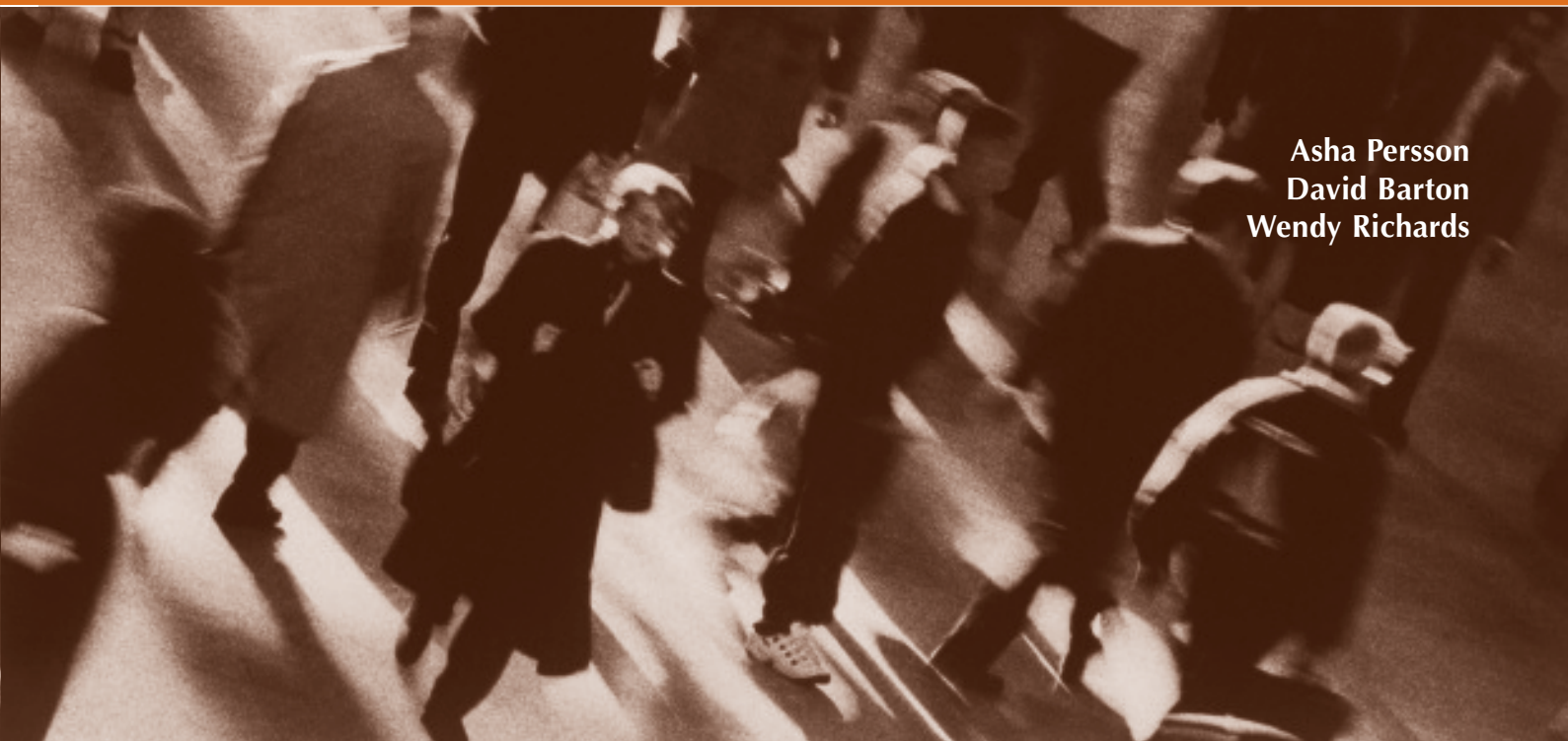


MONOGRAPH 2/2006

Men and women living heterosexually with HIV

The Straightpoz study, Volume 1



Asha Persson
David Barton
Wendy Richards

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Asha Persson¹
David Barton²
Wendy Richards³

¹National Centre in HIV Social Research

²Heterosexual HIV/AIDS Service NSW

³Pozhet PartnersPLUS, Sydney

'In the straight world, HIV makes you so foreign. You might as well come from Mars. Suddenly—splat—you've sprouted green horns. You turn into something else because there's nothing in their life that will prepare them for it. There's no HIV competence generally in the community.'

Maria, HIV-negative partner

National Centre in HIV Social Research
Faculty of Arts and Social Sciences
The University of New South Wales



Copies of this monograph or any other publications from this project may be obtained by contacting:

National Centre in HIV Social Research

Level 2, Robert Webster Building
University of New South Wales
Sydney NSW 2052 Australia

Telephone: +61 2 9385 6776
Fax: +61 2 9385 6455
Email: nchsr@unsw.edu.au
Website: <http://nchsr.arts.unsw.edu.au>

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Editor's note

Words in square brackets are editorial interpolations, made either to provide explanations or to preserve the anonymity of the interviewee. Ellipses (...) indicate an editorial cut, usually made because the interviewee repeated him- or herself or said something irrelevant to the point for which the quotation is being cited.

Summary

HIV places heterosexual people in a highly stigmatised position in heterosexual society. Fear of stigma and prejudice is a daily reality for many, and HIV shapes relationships and sexuality in profound ways.

In this report, 'people living heterosexually with HIV' includes HIV-positive men, HIV-positive women, HIV-negative partners, serodiscordant couples and families. The term is used to place emphasis on heterosexuality as a social practice, rather than as an identity.

People living heterosexually with HIV develop a range of strategies for building normality within a small, sheltered world of trusted people and within a wider world of indifference to and ignorance about HIV. They often feel like 'cultural outsiders' in the HIV sector and are generally disconnected from other positive people and from communal forms of dialogue and support around HIV.

The diversity and geographical dispersal of positive heterosexuals in NSW, the deep need to protect privacy and confidentiality, and the difficulties of accessing appropriate resources and support, create particular challenges for building a heterosexual HIV-positive community.

For heterosexual people, HIV is life-changing, with valuable insights and qualities fostered by the experience. However, the strictures of secrecy among heterosexuals living with HIV mean that these are not shared with the wider community.

Key findings

The key findings of the study are provided below under the major research areas.

Diagnosis and HIV-positivity

- Most participants had little awareness of HIV prior to diagnosis and attributed their ignorance about HIV to a lack of HIV education aimed at heterosexuals.
- It was uncommon for participants to be diagnosed at a sexual health or HIV clinic. Most were tested by their GP or at a suburban hospital or in other circumstances.
- None was diagnosed as a result of regular HIV testing. Many were late presenters.
- Many reported a lack of information and support at the time of diagnosis. Many also reported being asked unwarranted questions by health workers about how they contracted HIV.
- Being HIV-positive was an ongoing process negotiated through four intersecting modes: 'adjustment', 'disengagement', 'constraint' and 'defiance'.

Stigma and discrimination

- Many participants felt they were being forced into an 'identity corner' because of stereotypes associated with HIV in the heterosexual community.
- Participants experienced discrimination most often from health professionals.
- Some participants reported being treated differently by family members, friends or work colleagues, while some had experienced discriminatory treatment by government services, employers, the courts, police, the military and in prison.

Secrecy and disclosure

- There was a widespread sense among participants that HIV was so alien in heterosexual society that it was impossible to share, and that other heterosexuals lacked the necessary frames of reference to engage with it in a meaningful way.
- Participants created an 'invisible micro-ghetto', a tightly knit world of trusted people, drawn from immediate family members, close friends and primary health workers, within which they lived

and shared their HIV-positivity and developed strategies to 'pass' undetected in society.

- Within the immediate family, participants formed a smaller cell, the 'HIV family', who managed secrecy around HIV under highly constrained circumstances and for whom the rules of disclosure could be a source of tension.
- Social isolation was both a coping mechanism and a consequence of secrecy. Female negative partners and positive men in relationships tended to retreat into the HIV family, while single positive men were often extremely lonely.
- Positive women's accounts suggested a greater capacity to reach out for support and make meaningful connections with others.

Negotiating intimate relationships

- An HIV diagnosis contributed to the breakdown of existing relationships in the case of most positive participants.
- There was a gender difference in positive participants' capacity to form intimate relationships after diagnosis: positive women were generally more optimistic and active around building new sexual relationships than positive men.
- Single positive participants viewed disclosure to a sexual partner as a fraught process, preventing many from even trying to find a relationship.
- Most single positive participants were aware of the legal requirement to disclose to a sexual partner. Their capacity to disclose was compromised by the lack of a safe-sex culture among heterosexuals, the invisibility of HIV in heterosexual society, and its association with sexual deviance and the loss of the right to a sexual life.
- For couples in serodiscordant relationships (in which one partner is HIV-positive and the other is HIV-negative), living with HIV occurred primarily through two modes: 'sero-sharing', in which HIV was a shared experience, and 'sero-silence', in which HIV was less so.

Sex, sexual strategies and testing

- There were HIV-specific barriers to sex, including external and internalised stigma, difficulties around disclosure, ill health, depression, impotence, fatigue, body shape changes, social isolation and fear of infecting a partner.
- There was a notable difference in barriers to sex among couples. Those who had entered into a relationship

after diagnosis with HIV tended to enjoy an active sex life, while sex was much less common where diagnosis had occurred in an existing relationship.

- Sexually active couples used a variety of strategies to manage the tension between risk and desire, ranging from meticulous condom use to reinterpretations of safe sex, to denial or absence of a negotiated and structured approach to sex.
- Most negative partners did not test regularly. There was no obvious relationship between unprotected sex and testing.
- Appropriate resources and support are needed to increase skills in communication around HIV, disclosure to a sexual partner, and negotiating a serodiscordant relationship.

Services and community

- For health and medical needs, most participants accessed sexual health clinics and major hospitals.
- Most participants obtained their HIV-related information from their doctor, their HIV-positive partner, and Heterosexual HIV/AIDS Service mail-outs.
- The vast majority of participants had little or no contact with non-medical HIV services. Contact with services was more common in the early period following diagnosis, or during illness.
- Many participants felt that major HIV services were alienating, or did not meet their needs or provide specific support for heterosexuals, or for serodiscordant couples and families.
- Few participants had close friends with HIV and most had little or no contact with other positive people other than through peer support groups.
- Negative partners had significantly less access to peer support.

Positive futures

- Many participants felt that living with HIV had changed them for the better, that they had gained valuable insights such as acceptance, understanding and compassion and developed qualities such as adaptability, resilience and independence.
- Because of secrecy, these insights were rarely shared and could not play a role in bringing about change in the heterosexual community's attitudes to HIV.

Recommendations

In response to the findings of this study into living heterosexually with HIV, we recommend that:

- HIV/AIDS policy frameworks continue to address the invisibility of HIV, and the stigma and stereotyping faced by heterosexual people living with HIV, in the wider community
- the HIV/AIDS sector considers social marketing and media strategies to address broader social values behind the invisibility and stigma of HIV in the wider community, and to highlight HIV and diversity, for example in association with World AIDS Day
- resource allocation to the HIV/AIDS sector recognises the particular health education and support needs of people living heterosexually with HIV and ensures that appropriate levels of service and support are provided in response to these needs
- the HIV/AIDS sector ensures the continued development and availability of a range of print and web-based resources to:
 - support positive heterosexuals and their partners in negotiating a serodiscordant relationship
 - better inform negative partners about sexual health and HIV transmission
 - support and advise people in both casual and established serodiscordant heterosexual relationships about safer sex practices
 - increase the uptake of HIV testing by negative partners
- education and training programs for health professionals, including undergraduate medical degrees, incorporate education around HIV and diversity, to support appropriate service provision and reduce discrimination
- closer ties be developed between specialist sexual health clinics and divisions of general practice to ensure that heterosexual men and women who test HIV-positive with a GP receive appropriate HIV/AIDS information and support at the time of diagnosis
- HIV/AIDS clinical workers in hospitals and sexual health clinics who come into contact with heterosexual men and women who have recently been diagnosed with HIV help their clients to gain access to relevant HIV/AIDS services and support by providing resources and referrals in addition to the intervention taking place
- outreach services be provided to sexual health clinics and other agencies to increase local capacity to deliver peer support and education to positive heterosexual clients
- further research be undertaken into health, treatments, and interactions with health services, as well as into sexual practices and understandings of risk, transmission and sexual health, among positive heterosexuals and their partners
- the findings of this research be used to enhance the capacity of HIV programs and services to work effectively with positive heterosexuals, their partners and families.

Introduction

Background

An estimated one in five people with HIV in Australia identify as heterosexual, yet they remain largely invisible in Australian heterosexual society, as well as in the broader HIV epidemic, and little is known about their experiences of living with HIV. While HIV is a heterosexual epidemic in almost all countries, transmission of HIV in Australia has predominantly occurred through sexual contact between men. Thus the history of the HIV epidemic in Australia is closely linked with the gay community, which has been disproportionately affected by the virus. HIV prevention and education strategies have been primarily targeted at gay men, particularly over the past fifteen years (Kippax & Race, 2003). Meanwhile, HIV has gradually receded from mainstream awareness and today exists on the periphery of heterosexual society. It is not woven into language, relationships and awareness in the way it tends to be among many gay men.

An estimated one in five people with HIV in Australia identify as heterosexual, yet they remain largely invisible in Australian heterosexual society, as well as in the broader HIV epidemic, and little is known about their experiences of living with HIV.

However, surveillance data show that in 20% of new HIV diagnoses between 1999 and 2004 transmission was attributed to heterosexual contact (National Centre in HIV Epidemiology and Clinical Research, 2005). It is significant to note that transmission rates among heterosexuals have remained relatively stable over the past decade. It is equally important to point out that heterosexual transmission rates are not decreasing. In addition, lacking a culture of regular HIV testing that enables early diagnosis, heterosexual people constitute a substantial proportion of late presenters with an AIDS diagnosis (McDonald et al., 2003), as is the case also in the US, the UK and other parts of Europe (Giard et al., 2004; Manavi et al., 2004; Samet et al., 2001).

In the HIV literature, heterosexuality is discussed almost entirely in relation to perceptions of HIV among HIV-negative people, risk behaviour and transmission. There is a considerable body of research into the experiences of living with HIV, but there is a dearth of research specifically on the experiences of living heterosexually with HIV, not only in Australia but in culturally comparable countries such as Canada, England and the US. Heterosexuals are often subsumed within broader studies on living with HIV where their experiences are compared with those of gay men rather than understood in their own cultural or sexual contexts. Alternatively, they are segmented into studies focusing on specific groups within the epidemic, such as people from culturally and linguistically diverse backgrounds, women or, much more rarely, heterosexual men.

Interesting insights can be drawn from this literature. For example, one large American study found that heterosexual transmission of HIV was very low, but that male to female transmission was about eight times more 'efficient' than female to male transmission (Padian et al., 1997). Studies also suggest that many heterosexuals are misinformed about HIV and transmission (Herek et al., 2005). HIV is rarely regarded as a personal threat because heterosexuality tends to be normalised as 'safe' (Peart et al., 1996). Perceptions of risk are largely shaped by cultural and gender stereotypes, with 'risk' being associated with particular identities (gay men, drug users, 'sluts') rather than with particular practices (Patton, 1994, p. 121). Safe sex, therefore, becomes translated into avoiding sex with people associated with those identities. Young heterosexual men, especially, have been shown to believe in their own ability to select 'safe' and 'clean' female partners (Waldby et al., 1993a).

Studies also shed light on the lives of positive heterosexuals. For example, Australian studies have found that positive heterosexuals, men in particular, are significantly less likely than other people with HIV to know or spend time with positive people. Positive heterosexuals are also less likely to report having sex than

gay and bisexual men with HIV, and positive heterosexual men are less likely to be in an intimate relationship than positive women (Grierson et al., 2004; McDonald et al., 2002; Grierson & Mission, 2002).

The California Partner Study is one of the few published studies on serodiscordant heterosexual couples. This ten-year study found that couples struggled with multiple layers of stigma inside and outside their relationship, which often impeded communication and support-seeking. HIV-negative partners found it particularly difficult to access support that centred on their needs rather than on those of their partner (van der Straten et al., 1998). This and other international studies have also estimated that 25% to 45% of sexually active serodiscordant heterosexual couples engage in unprotected sex (Buchacz et al., 2001; Skurnick et al., 1998; Lansky et al., 2000; Semple et al., 2002).

HIV is socially marginal and stigmatised in heterosexual society where it tends to be ... typically stereotyped as a 'gay men's disease'. How do heterosexual people negotiate HIV-positivity in this context?

While the existing literature provides valuable findings such as these, there is a significant absence of qualitative research that recognises and explores heterosexuality as a social and cultural phenomenon that shapes how HIV is experienced and lived (exceptions include some studies with positive women, e.g. Squire, 2003; Lawless et al., 1996; Crawford et al., 1997). This recognition, and indeed the very concept of heterosexuality, is also largely absent from much of the language, media and educational material in the Australian HIV sector. The authors of this report recognise that experiences of HIV for heterosexuals are culturally different from those of gay men. Disclosure, relationships, sex, reproduction and community have different subtexts and priorities in a heterosexual context.

In addition, HIV is socially marginal and stigmatised in heterosexual society where it tends to be deeply coded by heteronormative ideas around gender and sexuality, and typically stereotyped as a 'gay men's disease'. How do heterosexual people negotiate HIV-positivity in this context? How does it shape their identity as social and sexual participants in heterosexual society? What are the implications in terms of health, quality of life, sexual

practice, relationships and sociality, or indeed prevention and health promotion for heterosexuals with and without HIV?

This study was initiated in response to this gap in the research and in response to a 2003 review of the longitudinal study Positive Health, also conducted by the National Centre in HIV Social Research (NCHSR). The review found that the previous inclusion of heterosexuals in the Positive Health cohort was unsatisfactory for two reasons: their numbers were too small to provide a basis for statistical analysis, and many survey questions were not particularly relevant to heterosexuals as the study was designed mainly with gay men in mind. It was therefore decided that all heterosexual participants should be removed from Positive Health and be invited to join the Straightpoz study instead.

The Straightpoz study is the first study of its kind in Australia. It is a qualitative longitudinal study with a cohort of 31 positive heterosexuals and negative partners in NSW. The study received ethics approval from the Human Research Ethics Committee at the University of New South Wales (UNSW) in 2004. The study is conducted by NCHSR in collaboration with the Heterosexual HIV/AIDS Service (Pozhet), the only service in NSW specifically for people living heterosexually with HIV. Positive heterosexuals have long been a hard group to reach for social research. The reason this particular study has been successful has been its explicit focus on heterosexual HIV. The close collaboration between NCHSR and Pozhet through each stage of the research has been another fundamental reason for the study's success.

This report presents findings from the study. These findings will hopefully go some way towards providing much-needed understanding of the complex issues facing people who live heterosexually with HIV and how social and cultural contexts shape those issues. It is hoped that educators and other service providers in the HIV sector will take up this research to gain a different insight into the experiences of heterosexual HIV, and that the issues highlighted here will provide a basis for further research and for the continued development of appropriate service provision for heterosexual men and women with HIV and their partners.

Method

Participants were recruited primarily through the Positive Health cohort and through an ad in *Talkabout*, a magazine produced by People Living with HIV/AIDS NSW, which is regularly sent to Pozhet clients. In-depth, semi-structured interviews were conducted between August 2004 and February 2005, including 29 face-to-face interviews and

two phone interviews. The interview schedules for positive participants and for negative partners were developed in close consultation with Pozhet to ensure that language, themes and questions were appropriate to the target group.

Nearly all participants asked to be interviewed at home due to confidentiality concerns, transport difficulties and convenience. The remaining four interviews were conducted at NCHSR, at a Centrecare facility and at the AIDS Council of NSW. The duration of interviews ranged from 20 minutes to three hours, with an average duration of two hours. Interviews were conducted in a conversational style and explored the following themes: key events around diagnosis; perceptions and knowledge of HIV prior to diagnosis; impact of HIV on identity and everyday life; negotiating HIV as a straight person in a straight world; stigma, disclosure and discrimination; relationships and sex; family and children; social connectedness and access to services and the positive community.

All interviews were audio-recorded and subsequently transcribed verbatim. Identifying information was removed from the interview transcripts or changed to ensure the anonymity of participants. Transcripts were coded for major themes, which were carefully analysed to identify similarities and differences across the interviews, both among and between the three main groupings: positive men, positive women and negative partners.

Two more phases of data collection are planned for the periods 2006/2007 and 2008/2009. The aim of each phase will be identified in close consultation with key stakeholders to ensure that the study is able to: respond to community feedback on previous findings and to new or emerging issues in the epidemic; track changes in the cohort over time, particularly in relation to health, sexual practice, relationships, serostatus of partners and pregnancy; and explore additional themes not covered in the first phase, such as health and treatments, understandings of risk, transmission and sexual health.

Participants

Thirty-one participants were interviewed, including 14 positive men, nine positive women, six negative female partners and two negative male partners. Despite several attempts, recruitment of additional negative male partners proved unsuccessful. Participants ranged in age from 24 to 70 years, with most in their 40s and 50s. They lived across and beyond Sydney, with a concentration in the inner and outer western suburbs. Two participants had recently moved interstate to the Northern Territory and Queensland, but were included because of their previous participation in the Positive Health study.

Among positive participants, nine men and three women were currently single, with one woman actively dating. Five men and four women were married or in committed relationships. Another two women were in new or tentative relationships. Five men and six women had divorced or separated since diagnosis and two men and one woman had been widowed by AIDS. In all, the study included 15 different couples. In the case of five couples, both partners were interviewed. Among the remaining 10 couples, only one partner was interviewed. In eight of the couples the male partner was positive, in six of the couples the female partner was positive, and in one couple both partners were positive. Two couples had recently separated and in one couple the partner had died.

The participants, including partners who were not interviewed, were from a range of cultural and linguistic backgrounds, including Anglo-Australian (the majority), English, Irish, Middle Eastern, Fijian, Maori, Aboriginal, African, Mediterranean, North European, East European, Chinese and Indian. The cohort spanned a wide range of socio-economic backgrounds and life experiences and included retirees, business owners, factory workers, military personnel, single parents, former inmates, born-again Christians and public servants.

Sixteen participants were parents, including five positive women, eight positive men and three negative partners. Between them they had 29 children, ranging from newborn to adult. Four children were born following their parent's diagnosis, with two being HIV-positive. The mother of one positive child was unaware of her HIV status prior to pregnancy. Two children were the offspring of serodiscordant couples. Two positive women were currently trying to conceive and one negative partner was pregnant. Among current couples, two children were brought into a serodiscordant relationship by a negative partner. Seven participants lived with dependent children. Two men (both widowed) and one woman were single parents.

Among positive participants, five were in full-time paid employment, one ran her own business, four did casual or part-time work, nine received the disability support pension, three received the old-age pension and one participant was studying. Five of the nine women worked, mainly full-time, while only five of the fourteen men worked either in a full-time or part-time capacity. Six of the eight HIV-negative partners were in full-time paid employment. Four positive men had spent time in jail, with three men having served time more than once.

Time since diagnosis ranged between one and 20 years, with an average of 11 years. Unprotected heterosexual sex was the most commonly mentioned mode of infection (10), followed by needle sharing (3), blood transfusion (1)

and other surgical procedures (1). One participant had no idea how he became infected and seven men were unsure. Of these, two believed that infection most likely occurred through a medical procedure, two said they were infected either through a medical procedure or through heterosexual sex, one man speculated that he might have been infected in a one-off needle sharing incident, another man said he was infected either through needle sharing or through sex with 'a drag queen', and one man did not volunteer any information.

Significant curiosity and widespread assumptions surround positive heterosexuals and how they became infected. Instead of focusing on this, we wanted to place emphasis on how they *lived* with HIV.

It is possible that some participants in this study wished to affirm a socially acceptable identity by denying transmission routes such as drug use or homosexual contact (see Sobo, 1997). Significant curiosity and widespread assumptions surround positive heterosexuals and how they became infected. Instead of focusing on this, we wanted

to place emphasis on how they *lived* with HIV. We also wanted to see how participants chose to tell their stories. In many cases, there was an apparent desire to control their story and self-presentation, so often wrested from heterosexuals with HIV. For instance, Angus, aged 51, who had a background of injecting drug use, emphasised that he was not infected through needle sharing, but through sex with his positive wife. The fact that infection took place in the context of love was very important to him.

Many participants, mainly male, were late presenters. Nine of the fourteen men had had a late diagnosis, with several being informed that they had possibly been HIV-positive for eight to ten years. As a result, the health of many men in the study was poor, with several suffering a number of illnesses and complications. Depression was more commonly reported by the men than the women. Thirteen of the fourteen men were on HIV treatment, compared to five of the nine women.

The authors acknowledge that the lived experiences of positive heterosexuals and negative partners are diverse and complex. Consequently, the research findings presented here should not be seen as representative of all people living heterosexually with HIV in Australia, nor should the stories of participants in this report necessarily be seen as straightforward reflections of lived experiences or as unproblematic windows onto a particular subjectivity, but rather as contingent, contextual and often ambivalent narrative constructions of what it means to live with HIV.

1 Diagnosis and HIV-positivity

Circumstances and prior knowledge

The invisibility of HIV in heterosexual society was evident in the circumstances of the participants' diagnoses. No one was diagnosed as a result of regular HIV testing. Illness was the most common reason for having an HIV test, particularly

[The doctor] looks at me and he puts his hands on my shoulders and goes, 'I'm really sorry to tell you. You've been diagnosed with HIV.' And I went, 'With *what?*' I just didn't get it.

among the men. Other reasons included diagnosis of a partner, donating blood, being notified of exposure, and routine testing in relation to incarceration and military deployment overseas. Only two participants were diagnosed during seroconversion illness. Most were utterly shocked to learn that they were HIV-positive. Cameron, aged 43, described being told his HIV test results in 2003:

[The doctor] looks at me and he puts his hands on my shoulders and goes, 'I'm really sorry to tell you. You've been diagnosed with HIV.' And I went, 'With *what?*' I just didn't get it. I just plain didn't get it. I sat there and he's talking and I couldn't hear a word he was saying. I was looking at the wall, trying to think, treading my steps back ... It was like being accused of murder and you're trying to think of your alibi ... I was trying to think, you know, how, where, when?

Those who were diagnosed in the era of the 1987 Grim Reaper advertising campaign believed HIV was a 'death sentence' and described the experience as terrifying because of the fear that characterised the time and because of a lack of peer support for positive heterosexuals. Many participants, including those who were diagnosed more recently, had little understanding of what

an HIV diagnosis meant for their lives in terms of health, longevity, reproduction and sexuality. Ellen, aged 43, tested positive in 1995:

Initially, 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.

Prior to testing positive, most had little or no awareness of HIV and very few knew somebody who was HIV-positive. Those who did were mainly participants who had moved in drug circles. While participants knew of HIV from television and newspapers, HIV was simply not part of their world. Except for those with a history of injecting drug use, few had ever considered HIV as a personal concern or risk. In retrospect, Grace, aged 64, who tested positive eight years ago, was surprised about this:

I suppose I really should have thought about it, but it's something you *don't* think of. Or *I* didn't ... It was just something that was in the background and really I didn't know a lot about it ... It's amazing, really, that you can go through life like that.

It was relatively uncommon for participants to be diagnosed at a sexual health or HIV clinic. More often, they were tested by their GP or at a suburban hospital or in other circumstances. A lack of information and support at the time of diagnosis was mentioned by many, both among those who were diagnosed in the early years and those diagnosed more recently. Many participants reported being queried by health workers about transmission. Those who were unsure or who denied drug use, homosexual contact or other forms of stigmatised sex often felt they were met with scepticism from doctors and hospital staff. 'Their assumption was that I'm some kerb-crawler or something,' Cameron said.

Reactions to diagnosis

The time following diagnosis was often tumultuous and traumatic, sometimes for several years. 'It just felt like the world swallowed you into this big black hole,' Audrey, aged 36, said. Depression was common among both men and women, as were feelings of shame. Stigma and gender roles tended to shape reactions to diagnosis. For example, the women's accounts of their reactions were often framed by cultural stereotypes that position women as 'dirty', 'polluted' and 'infectious' (Waldby et al., 1993; Lawless et al., 1996). Olivia, aged 33, tested positive when she was eighteen years old:

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.

The men were more likely to describe a chaotic time of anger, disengagement and self-destructive behaviour, when they would withdraw from social contact, begin heavy drinking or fall back into drug use. Many found it extremely hard to accept their diagnosis, with several men attempting or contemplating suicide at the time. In contrast to the women, there was a reluctance to seek help or counselling, a common finding in studies of men and health (Taylor et al., 1998; Addis & Mahalik, 2003). However, a lack of appropriate services for positive heterosexuals was another significant barrier. When Mahmoud, aged 30, became infected shortly after completing a jail sentence, he 'went crazy', started using drugs again and landed back in jail:

Because coming out from jail, like to fix my life up, because everything was good, you know, I was proud of myself because I went so good; I did heaps of things in there, like education, stuff like that, give up smoking, give up drugs, give up everything. Come out and then, like copping a life sentence, you know. That really devastated me, you know. I mean, it still affects me now. I still cry about it now but not as much. I just didn't want to be here no more. But lucky I had people that loved me and that. And lucky I had my son, because if my son wasn't there ... I would have just went. But, yeah, I was sort of living for him.

Participants eventually found ways to live with HIV. Some turned to family for support or, like Mahmoud, decided to live for their children. For others, information, counselling or peer support helped them process their feelings around being HIV-positive. Some threw themselves back into life, into careers and relationships, while others isolated themselves to cope or to avoid difficulties posed by HIV.

Modes of positivity

Testing HIV-positive was not something participants simply 'worked through' and then moved on from. There was no straightforward progression from despair to regained confidence, or a coherent reconstruction of identity and meaning. Narratives of denial and acceptance, of empowerment and disempowerment, of optimism and dejection were interwoven in each interview (see Squire, 1999). While many described a desire to 'get on with life', HIV-positivity was an ongoing process of negotiation. In this process, four modes of positivity were prominent, which we have named 'adjustment', 'disengagement', 'constraint' and 'defiance'. These modes were not mutually exclusive; rather, they often intersected in the interviews.

Adjustment

By far the most common mode of HIV-positivity was acceptance and trying to accommodate HIV, without allowing the virus to limit or dominate life. Often coupled with taking steps to access support and health care, there was a strong emphasis on returning to normality, on maintaining a 'positive attitude' and 'not dwelling on it'. For example, Ruby, aged 34, said:

I've always been a laid-back, easygoing, get-on-with-it sort of person ... Like, I look at the good side of things or situations or try to make the most of it. I can't change it, so I work around it, work with it ... everyone's probably different in how they handle it ... I mean, I do have times where I'll just have a good cry, but that doesn't last long. It's just, 'Come on! Get on with it!'

Disengagement

Disengaging from HIV was also common and was partly a result of HIV's receding into the background in the absence of any concrete symptoms or any daily reminders such as medication. At other times, disengagement was a deliberate strategy of mentally blocking out HIV, of denial. This mode had quite different potentials; it was positive in that it enabled a sense of 'normality', but it also made participants and couples potentially vulnerable, especially if they disengaged from services and support. The following account was by a participant who was on treatments, had regular contact with health services, but who did not practise safe sex with his negative female partner:

I shut it out of my life now, I try to anyway, like pretend it's not even there. Like I still look after myself, you know, and be healthy, but I just shut it out of my life,

like I haven't got it, you know? That's it. I don't want to know about it ... I just live my life normally. I don't even want to live like I've got HIV, so I don't want to know. That's the way I've dealt with it. That's the only way that makes me feel comfortable.

Constraint

In this mode of positivity, the desire to get on with life was constrained by HIV. Life became dominated by a daily struggle with debilitating illness, medication, regular hospital visits, secrecy, isolation or poverty. Alternatively, HIV was experienced as a loss of control over life choices and destiny, as Donna, aged 47, explained:

What disturbs me the most about my life being HIV-positive is that I'm not in the driver's seat. I'm a passenger in life. I *cannot* make the decisions that everyone else takes for granted ... I'd like to go on safari in Africa. I'd like to be able to choose to spend six months of the year in Greece. I cannot do those things ... I can't go and live [overseas] with my son because I can't afford the drugs and I can't buy the drugs there because I don't have health insurance there ... The disease controls my life and it controls where I live, it controls how I live ... I can diet as much as I like, I'll still have a heavy trunk. I can go to the gym as much as I like and I still won't have a butt. I can put all the lotions and potions on my scalp and I still won't have hair. I can cook as healthy a food as I possibly could ... but that's not going to make me well ... It concerns me enormously that I'm not in control of my own destiny.

Defiance

In the fourth mode, participants expressed a sense of defiance towards HIV. They refused to let HIV define their life or identity and were determined not to give in mentally and emotionally. Brendan, aged 46, said:

I've been shot, bashed and stabbed and I'm still here. Fucked if I'll let a little virus beat me. That's my philosophy. I just *won't* give in. But, as you know, there's times when you hit low, when you think, 'Fuck it, I've had enough'. But there's this little dude in the back of your head going, 'Get the fuck up,' you know, 'you can't admit defeat'. That stems from the nick. You can't show fear, you can't show any weakness, because they'll fucking swoop on it.

The impact of HIV was not uniform, but rather relative and diverse. Depression and other mental health issues were a far bigger problem for some than HIV. Others explained that HIV was merely one among many difficulties in their lives, that drug addiction, jail, sexual abuse, disability and death put HIV into perspective. One man said that HIV was a turning point for the better: 'It gave me a life.' Angus, aged 51, described his life prior to HIV as 'shit', an endless cycle of drugs and jail stints. His diagnosis coincided with his caring for his dying wife and their newborn son:

I mean, it might sound strange but getting the virus led to [my son] coming along, which led to me getting rid of the lifestyle that I thought I'd end up dying in jail or dying with a needle or something. I look back now and I think, 'God, I survived it!'

Whatever mode or impact the participants described, HIV was typically seen as 'life-shaping' (Herek & Greene, 1995; Squire, 2003). They spoke of multiple and profound ways in which HIV came into play and either caused or complicated particular life experiences, including physical and mental health, treatment side effects, family life, social isolation, career opportunities, inability to work and poverty. However, there were two areas of life in which HIV came most prominently into play—disclosure and relationships (Chapters 3 and 4)—and both were inextricably linked with stigma.

2 Stigma and discrimination

Testing positive reinforced the sense of HIV as a marginal issue in heterosexual society. There was a consensus that most heterosexuals were uninformed and ignorant about HIV, or that they simply didn't think HIV concerned them. Most participants admitted to a similar mind-set prior to testing positive or meeting their HIV-positive partner. Claire, a negative partner, explained: 'I didn't know anything about it ... I just thought, "Oh, yeah, gay men get it and the lifestyle that they lead, it's no wonder."' There was not a lot of sympathy.' Similarly, Morris, aged 58, was convinced his HIV test would be negative because he was a heterosexual man:

[The doctor] came and said, 'I want to do a test for the HIV. Do I have your permission to do it?' and I said, 'Oh, no problems. I haven't got it anyway' ... [I was] ignorant about the whole thing. That's why when the doctor said he wanted to do the test I said, 'I won't have it; I'm not gay, there's no way' ... I thought a hundred per cent I wouldn't have it. I have found out since that a *lot* of people that are not gay have it, *a lot* of people, even women have it.

Participants thought that social attitudes towards HIV had changed since the Grim Reaper era, yet most believed that HIV was far from normalised or accepted among heterosexuals.

Participants attributed their prior ignorance or prejudices to a lack of HIV education aimed at heterosexuals. There have been very few national HIV prevention campaigns in Australia, and HIV is rarely represented in the media as a heterosexual concern. Since the early epidemic, the media emphasis and educational campaigns have primarily centred on gay men. This briefly changed in the late 1980s, when the media suddenly focused on the threat posed by HIV to heterosexuals (Lupton, 1992,

1999, p. 40). The infamous 1987 Grim Reaper ad marked this period and was the first national public health campaign in Australia to promote heterosexual awareness of HIV transmission and safe sex. It was a distinctive moment in the history of HIV in Australia and the Grim Reaper has become a defining figure in the Australian AIDS culture (Vitellone, 2001).

The Grim Reaper was mentioned by many participants as the only exposure to any kind of HIV awareness that they could remember. Contrary to the interpretation that the campaign effectively disassociated HIV from homosexuality (Lupton, 1992, 1993), it was widely felt that the ad merely fuelled fears and misconceptions among heterosexuals and reinforced, rather than decreased, homophobic constructions of HIV. Gavin, aged 46, who was diagnosed in 2000, was unaware that he was HIV-positive at the time:

I think one of the bad things about it was the government put an ad out years ago about the Grim Reaper and, you know, like 'if you basically come into contact with HIV people, you're dead! You've got no hope'. That stuck in a lot of people's minds. At that time I didn't know I was HIV-positive and that actually scared me too. I don't think it really stopped anybody from doing anything ... It more turned people against the people with HIV ... It was the homosexual or the drug user who was going to give it to you. Even though you're heterosexual, you're going to get it. Well, that's how the ad came across to me. You know, that put a stigma against gay people a lot with me, because they carried it all ... under that cloak was a big gay bloke and *he* was going to give it to you.

Participants thought that social attitudes towards HIV had changed since the Grim Reaper era, yet most believed that HIV was far from normalised or accepted among heterosexuals. 'It's an illness that people just rather not know about,' Claire said. Indeed, participants perceived HIV as

highly stigmatised in heterosexual society, insisting that people were generally still frightened of the virus and prejudiced against those who contracted it. Many blamed this on a lack of education about HIV. At the same time they struggled to come to grips with the homophobia and 'politics of sexual shame' (Warner, 2000) that besiege heterosexuality and, by implication, fuel the stigma of heterosexual HIV.

Everybody seems to think, 'You're HIV? You're gay! You're not gay? You're a drug user then.' You know? Can't they get it any other way? Is that the only two ways in the world? You know, they don't realise...

The stigma of heterosexual HIV

Much is written about stigma but Erving Goffman's *Stigma* remains the authoritative work. He defined stigma as an 'attribute that is deeply discrediting' (1963, p. 3). Those who are seen to possess it experience loss of status and acquire a 'spoiled identity'. He was careful to observe that stigma is fundamentally about social relationships, not individual attributes, visible or otherwise. Goffman's work has provided a basis for much subsequent theorising of stigma (for a review, see Deacon, 2005; Link & Phelan, 2001). The definition most useful here is that of stigma as a social process of differentiation and blaming, driven by power and fear.

Stigmatisation is an 'emotional response to danger', such as disease or a perceived threat to the moral order of society (Deacon, 2005, p. 18). Blame for the peril at hand is assigned to 'others', often socially marginalised groups. Stigma commonly relies on well-established stereotypes, following existing patterns of inequality and prejudice, such as homophobia, sexism, classism and racism (2005, p. 8). In the stigmatisation of HIV/AIDS, the cultural fears and anxieties evoked by disease (contagion, death) are reduced and the perceived loss of control alleviated as the threat of disease is projected onto 'others' (gay men, drug users, sex workers). These 'others' are attributed with deviant characteristics (depravity, promiscuity) that are deemed to be the source and conduit of disease, thus distancing and protecting the social 'in-group' from risk, responsibility and blame (Deacon, 2005, pp. 22–23; Crawford, 1994; Gilman, 1988, pp. 1–3).

This theme was echoed by many in the study. Simon, a 35-year-old negative partner, said: 'I think they see it as a certain sort of people who get it ... they've got it because it's their own fault. A lot of people still see it that way.' The stigma of heterosexual HIV was overwhelmingly thought to derive from its association with socially unacceptable practices, primarily drug use and the 'wrong' kind of sex: promiscuity, infidelity, prostitution, homosexual contact. Because such practices are censured in heterosexual society, they are often secretive, private and besieged by guilt, thus compounding the shame of heterosexual HIV. Regardless of whether or not infection occurred through such practices, many participants felt they were being forced into an 'identity corner' and denied ownership of their self-presentation. Gavin's comment was typical among the men:

Everybody seems to think, 'You're HIV? You're gay! You're not gay? You're a drug user then.' You know? Can't they get it any other way? Is that the only two ways in the world? You know, they don't realise, you know.

Similarly, Ellen, a mother who worked for an international company and lived on Sydney's north shore, reflected on the cultural stereotype of HIV-positive women:

They're sort of promiscuous, a bit dirty, undesirable, that kind of thing ... I think people still really don't know very much. You know, I think if the mums at school knew that I have it, they would just fall over. They wouldn't expect it, you know, because I don't fit into the model of who has HIV.

'Courtesy stigma' (Goffman, 1963, p. 30), or stigma by association, was described by many partners. Female partners, in particular, said their relationship with a positive man was provocative to many people and often met with bewilderment or curiosity, even anger and disdain. They told stories of being lectured by friends, colleagues and health professionals about their 'irresponsible' and 'foolish' behaviour. Not only were they wasting their lives, their choice of partner was a sign of their own morally corrupt character. Maria, aged 53, met her partner 15 years ago:

It was very interesting in the early days and I guess still now, but I could feel people thinking to themselves that I was either mad or carnal. I was either sexually demented or I was intellectually bereft to have a relationship with a positive man ... People who are positive are depraved, they have done a depraved thing, and people who go with them, it's like going to a leper colony, you know, they're doing a depraved thing as well. They're going down into the gutter ... *depraved* by association.

For the men, the cultural inscribing of HIV as 'gay' was experienced as a loss of identity. Feminist writers have argued that the formation of gender identity emerges out of negation. Heterosexual masculinity is defined by what it is not, by what it rejects, above all, femininity and homosexuality. It depends on the repudiation of these identities for its own security and coherence (Butler, 1997). The men responded to this destabilising of identity in several ways. Many emphasised the 'commonness' of heterosexual HIV as if to reinstate their own identity: 'There are so many straight people that have got HIV, it's not funny,' Kevin, aged 57, insisted. 'It's amazing the cross-section of the community that does have it.' Secondly, they expressed resentment towards the homophobia underpinning HIV stigma. Tobias, aged 51, worked in the hyper-masculine milieu of the military:

If I went in to work and said, 'I'm HIV-positive', they'd baulk because it is aligned with the gay side of the community ... They'd say, 'Shit, we never thought Tobias was a poof' ... [That] doesn't make me resent either HIV or the gay community. It only gives me more sympathy for them.

Their own experience of stigma had sensitised many participants towards marginalised groups. Expressions of empathy and understanding were common. In contrast to discourses prevalent in the early epidemic, none spoke of being an 'innocent victim', except for one woman infected via a blood transfusion in the 1980s. They were more likely to speak of themselves as 'just unlucky', as having 'made a mistake', or use normalising language such as 'HIV can happen to anyone'. Such narratives suggest an attempt to absolve oneself of complicity in social prejudices when trying to come to terms with oneself as a person with HIV. Lucy, a negative partner, made this point:

They've had to suddenly turn their attitudes around. And that's very hard, too, for many people who've internalised all those kinds of 'Nothing to do with me' and 'It's a pretty low-life group of people who get this disease'. And then suddenly, 'Oh, my goodness! I'm one of those people.' I think part of that is the shame, too, because they've internalised those sorts of societal attitudes and suddenly they're having to find how to be okay with themselves. It's *very* hard, because they're turning those judgments on themselves and saying, 'Yeah, I've made a major mistake here; I was with the wrong person' or 'I did the wrong thing', whatever it happens to be.

Internalised stigma and discrimination

Stigma, as Goffman (1963) observed, shapes how people negotiate their identities and how they live their lives. Self-

stigmatisation involves a degree of acceptance of society's prejudices against oneself. If people are already socialised to subscribe to those prejudices prior to being stigmatised themselves, internalisation of stigma may be particularly difficult to resist. If people believe that others will reject and devalue those with HIV, they may expect that this rejection will now apply personally (Link & Phelan, 2001, p. 373). In Goffman's words (1963, p. 7):

[T]he standards he has incorporated from the wider society equip him to be intimately alive to what others see as his failing, inevitably causing him, if only for moments, to agree that he does indeed fall short of what he really ought to be. Shame becomes a central possibility, arising from the individual's perception of one of his own attributes as being a defiling thing to possess.

Internalised stigma was evident in most interviews, particularly among those who were diagnosed in the era of the Grim Reaper. Their stories clearly articulated how cultural representations of HIV such as 'death' and 'infectivity' could be taken up by positive people and be highly formative of their attitude to HIV and to themselves as people with HIV. Many found this internalisation of cultural discourses hard to shift, even with the benefit of current knowledge. Meagan, aged 45, said this of the Grim Reaper ad:

Yes, it gave me terrible hang-ups for five years ... like if you were to pick up my mug now and start drinking from it, I'd have a problem. I wouldn't stop you because I'm aware of the fact that it's perfectly safe for you to do that. I would still have a problem ... Yes, it's still there. 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.

Direct experiences of HIV-related discrimination were relatively uncommon among participants. This might be explained by the fact that they generally kept their HIV status secret and therefore did not expose themselves to potential discrimination. Many were extremely reluctant to disclose to anyone, precisely *because* they assumed that others would reject or discriminate against them if they knew their status. Deacon refers to this as 'perceived' or 'expected' stigma and discrimination (2005, p. 35). Stigma, she argues, is a social ideology that *may* lead to discrimination depending on the existence of an enabling context, but there is no direct or automatic relationship between the two (2005, pp. 17–18, 23). Hence, people with HIV 'respond to stigma and discrimination based not only on their own experiences, but also on what they encounter in the media and hear from others' (2005, p. 36). This was evident among the participants who told many stories of hearing colleagues or relatives speak disparagingly about people with HIV.

However, stories of direct discrimination were by no means absent from the interviews. While many participants praised the medical profession for its professional care,

There's still curiosity from health professionals about it when they don't even need to know. 'Why? How? What did you do? What happened? How did you get it?'

compassion and support, by far the most frequently mentioned instances of discriminatory treatment were in relation to interactions with health professionals. The most common forms of discrimination were breaches of confidentiality, being treated with suspicion or curiosity by doctors and hospital staff, and having assumptions made about how they became infected, or about the HIV status of partners. Lucy, a partner, observed:

There's still curiosity from health professionals about it when they don't even need to know. 'Why? How? What did you do? What happened? How did you get it?'

Some spoke of being treated differently from other patients or, less commonly, being treated last, or even being refused treatment. Audrey, 36, said:

I've noticed that, if I am in hospital or go to the dentist or anything, being HIV, I am always, always last in surgery. I was the last person on the list when I had my Caesarean and yet there were four of us having our babies on the same day and that makes me angry ... That's one thing

with this virus that's really affected me, that you're always last for all your appointments, being treated differently in the hospital ... It feels like you have to educate *them*, rather than them being there to look after *you*.

Discrimination by the health profession dominated, but other forms of discrimination also occurred. Some described harassment by work colleagues, or spoke of discriminatory treatment or breaches of confidentiality in prison and in the military, by courts, police, government services and employers. There were also stories of being treated differently by family members or friends. Mahmoud, for example, said:

Like my family when I first told them, they made me—I couldn't stand it, I had to get away from them, because like every time I used a towel or anything, they'll ... like when I go in the shower and they go, 'Which towel did you use?' you know. I can *feel* them, you know. I just got away from them, just got out of there, just got my own unit and that.

Direct discrimination is not the only way stigma impacts on people's lives. Discrimination also operates through internalised stigma by encouraging stigmatised people to 'believe that they should not enjoy full and equal participation' in life, be it social, economic, sexual or otherwise (Link & Phelan, 2001, pp. 379–380). Stigmatised people may be disadvantaged as a result of how they organise their lives to avoid stigma or avoid situations that they think will be discriminatory (Deacon, 2005, p. 31). The literature identifies a number of strategies as common in managing a stigmatised identity, such as secrecy, concealment, social isolation and *passing* as 'normal' (Goffman, 1963; also Grove et al., 1997; Stanley, 1999; Weitz, 1991). The following chapter explores these strategies and how they shaped the participants' lives.

3 Secrecy and disclosure

The 'invisible micro-ghetto'

Secrecy was a major theme in the interviews and there was a tendency to keep HIV strictly separate from most aspects of life. Secrecy was both enabling and constraining. It provided protection from the possibility of stigma, upheld the semblance of a socially normative identity

Over time, the participants created for themselves what is termed here an 'invisible micro-ghetto', a space where HIV-positivity, meaning and identity were negotiated and shared through relationships with others.

and enabled a sense of normality. But it also entailed an unaccustomed censoring of the self and the need to find new forms of self-presentation and new ways of relating and communicating, a process that was commonly seen as difficult and isolating. In this process, participants had to develop a number of strategies and skills, including the ability to: gauge whom they could trust; determine how and when to tell; conceal and control information about their HIV status in order to 'pass' undetected in society; develop coping mechanisms; find emotional and professional support; and develop ways to manage secrecy with those who came to share their secret.

Over time, the participants created for themselves what is termed here an 'invisible micro-ghetto', a space where HIV-positivity, meaning and identity were negotiated and shared through relationships with others. This micro-ghetto was typically made up of a small group of people with whom the participants had not only shared their secret, but had also built, with varying degrees of skill and success, a language, culture and practice around what it meant to be positive and to live a 'positive' life. Unlike more traditionally known ghettos, the micro-ghetto was invisible to the outside world, having no physical border or socially recognisable behaviours or attributes that signalled its presence. Yet, it existed in real

time and space, in places such as homes, doctors' waiting rooms and peer support settings, crossing the public/private divide. It existed wherever the participants acted out disclosed, meaningful and committed relations with others.

Members of the micro-ghetto were typically drawn from the immediate family and/or close friends, but also included individual primary health workers and other sources of support, such as work colleagues or members of a faith community. Membership was largely based on trust, existing family bonds or professional roles. However, it rarely included other positive people, as very few participants knew positive people or kept in contact with them outside peer-support settings. Nor did the micro-ghetto necessarily include all people who knew the participants' status, for example, colleagues, friends, or even family members, as inclusion was primarily defined by engagement, to a greater or lesser extent, in living with HIV.

Members of a micro-ghetto did not necessarily know each other, but were likely to know *of* each other. However, for the participants, each member of this exceedingly personal space was vital in helping to build a life that included, rather than excluded, the realities of living with HIV. Some members of the micro-ghetto, in particular partners and immediate family members, participated intimately in the participants' positive status and were as deeply invested in protecting themselves against stigma. In this space, new identities and new ways of being were gradually crafted, through trial and error. Rules of disclosure were defined, and methods of camouflage and skills in 'passing' were developed and shared. This was often the space in which participants felt most authentic, relieved of the pressures of pretence and dissembling. But, because of its relational dimension, it was also a continually negotiated space and therefore, at times, marked by tensions and ambivalence. This chapter describes some aspects of building this micro-ghetto and the dynamics within it.

To tell or not to tell

[T]o tell or not to tell; to let on or not to let on; to lie or not to lie; and in each case, to whom, how, when, and where (Goffman, 1963. p. 57).

Disclosure was the primary mechanism for building the micro-ghetto. However, because of the perceived stigma and marginality of HIV in heterosexual society, most participants viewed disclosure as a highly fraught and dreaded terrain and were generally firmly disinclined to reveal their status (see Holt et al., 1998; Mansergh et al., 1995; Petrak et al., 2001; Paxton, 2002; Serovich, 2001). Many were convinced that most people in their lives would not be 'HIV literate' enough to cope with disclosure in an informed or supportive way. Most participants had disclosed only to a chosen few, and often only after considerable deliberation and agonising. Those most commonly confided in were close friends and the immediate family (mother, father, siblings). In some cases only one close family member was entrusted, most commonly their mother or a sibling. The extended family was rarely told.

Only a few had confided in people other than family and friends. These people included priests, former partners, work bosses and work colleagues, their partner's family, or acquaintances in their church, social clubs or former drug circles. Family and friends were also the two most common groups disclosed to by negative partners. However, their sphere of disclosure was usually even more restricted than that of their positive partner (see below).

Disclosure was primarily driven by a need for support and a need to confide in someone, to 'let it out'. The decision to tell family was also driven by societal notions of familial allegiance: 'I think in one way I felt they had a right to know ... you know, they are my family,' said Gavin. Disclosure also occurred in situations in which participants felt others needed to know or had a right to know, primarily health professionals and sexual partners, and in a few instances a work boss in the event of an accident.

A substantial minority had decided not to tell significant others, including family they had close contact with or friends they had known for years. Fear of rejection was relatively common, as were concerns about the ability of others to cope with the information. Some felt there was no real need for their families to know, especially if they were well. Others felt that too much time had passed since their diagnosis and feared that a belated disclosure might upset their family. Wanting to avoid pity or well-meaning advice was also mentioned. But the most common reason was a wish not to worry or burden loved ones, particularly young children and elderly parents. There was a sense that

by confiding their secret they would unfairly force others into secrecy as well.

About half the parents in the study had disclosed their own or their partner's status to their children. Of these, three currently lived with dependent children and five had adult children. Six of the parents had told their children at diagnosis or shortly thereafter. In two of these families, the children were adult at the time of disclosure. In four families, the children were young. These parents said they wanted their children to grow up in an 'open and honest' home. It is noteworthy that, in all four families, the other parent had died of AIDS or, in one case, a drug overdose, and two families included an HIV-positive child. The remaining two parents had waited until they felt their children were mature enough. Donna, who was infected via a blood transfusion at the time of the complicated birth of her son, told him when he was twenty years old:

I figured he was old enough to know. I chose not to tell him up until that date because I wanted him to have a childhood and I wanted him to just be burden-free ... and also, how I got the virus, I was very concerned that he would blame himself ... I said to him, 'I've got something terribly important to tell you that I've hidden from you all your life, for a good reason.' He said, 'I'm adopted' [laughs]. He was so sweet ... He was fine about it. He *never* asks me about it. But I think he thinks I'm pretty amazing.

Seven parents had not disclosed their own or their partner's status to their children. Of these, three lived with dependent children and two men had young children who lived with their mothers. They reasoned that they did not want to expose their children to potential prejudice and most were unsure whether they would ever tell them, unless forced to due to illness or the threat of disclosure by a third party. Mahmoud, 30, said: 'See, he's only nine years old ... I don't know when I'm going to tell my son ... He's got enough problems at school as it is, so I don't want to put any more stress on him.' Another concern was the ability of small children to manage the information and understand the implications of disclosure to other people.

Others feared the reaction of their adult or teenage children, worrying that they would think less of them, as Grace, aged 64, said: 'It's too scary to think of.' Issues around masculinity sometimes came into play in decisions around disclosure to sons. Derek, aged 56, for example, described himself as a once-successful businessman who had fallen on hard times since being diagnosed with HIV and bipolar disorder. He had decided not to disclose to his teenage son until he was back on his feet again: 'I'll tell him when I'm a success. But I can't tell him at the moment because at the moment he would just say, "Oh, well, Dad's just a total write-off."'

Bad experiences of disclosure in the early, vulnerable period following diagnosis were another relatively common reason for non-disclosure, particularly among men. A negative response from a trusted friend or family member had devastated them and they resolved never to disclose again. Conversely, some had disclosed indiscriminately early on and later regretted it. This occurred in the context of having recently received their diagnosis, feeling confused and desperate. Mahmoud, 30, for example, told a lot of friends and acquaintances because he was 'freaked out'. Most people were supportive but some became uncomfortable or hostile. Word got around and Mahmoud was confronted by members of his cultural community. He now wished he had not told so many people:

Well, from now, I'm not going to tell anyone anymore. That's it! I've got my partner; we're going to get married. I don't want to tell anyone anymore. I'm just sick of telling people. Because I don't want to put people through this, you know, like I have to go through it all over again and talk about it. So, no, there's no one that I want to tell. I just wish, some of the people I told, I wish I'd never told them. I wish I knew that before ... I should have only told the people that I sleep with. That's it! You know? Other than them, I should have just shut my mouth. Yeah, I made a mistake and I've paid for it.

I don't hide it. I'm straight out with everybody ... that way they'll know straight away ... They'll deal with it or they won't straight away. And I don't have to beat around the bush and buggerise around wondering, 'Can this person cope if I tell them?'

Participants told some heartbreaking stories about disclosure gone wrong, but also many positive ones. While it was never seen as an easy task, those who did disclose were generally quite surprised that friends, family or potential partners were often much more accepting and supportive than they had anticipated. Several participants emphasised the importance of telling a few well-chosen and trusted people. This was seen as important in terms of having someone to talk to, but also to have someone affirm 'that you are still you, and that you are okay', as Evan, aged 43, described it, a reaction he found very helpful when he disclosed to his close friends:

It was exactly that, being treated exactly the same as before which is, I guess, the important thing for everybody, to tell somebody, even if it's not your family, tell someone you've known for *years* that you're really good mates with ... They said, 'You're the same person we've always known. Want a cup of coffee?' and just carried on like normal, you know? I would recommend that. Actually I'd make that a very strong recommendation: if you don't want to tell your family, tell someone that you're close to and have known for years and years and years and, well, hope you get the reaction I did.

Favourable reactions to disclosure were generally described differently by men and women. Men described good reactions to disclosure as 'accepting' and 'supportive', signified by comments such as, 'Don't worry about it' or 'You poor bastard'. Women, including female partners, articulated ideal reactions by friends and family more in terms of 'understanding' and a compassionate, empathic acknowledgment of their situation.

The dynamics of disclosure

While HIV was generally a well-kept secret, the dynamics of disclosure were differently shaped by personal histories and social positions. Those who were already familiar with a stigmatised identity, primarily through injecting drug use or imprisonment, tended to be less protective and more open with their status, with a 'take it or leave it' attitude. But few were completely 'out' about their status. Angus, 51, and his young son Leon, also positive, led very public lives: they had appeared on television and in newspaper articles on several occasions, and Leon was a spokesperson for various charities for children with life-limiting illnesses.

They know if they want someone to sit there on TV and be openly honest about it and not give a damn about whether the whole world's watching and is going to know I have it, they know to come to me.

(Angus, HIV-positive)

Angus and Leon had experienced few negative consequences of their openness. In fact Leon had acquired a wide circle of supportive friends, including several celebrities. The only other participant who was entirely 'out' was Fiona, 50. She had encountered a range of reactions, but more often people were 'fascinated'. While she disliked being treated as a 'curiosity', being upfront was a conscious strategy to reduce stress around disclosure:

I don't hide it. I'm straight out with everybody. In fact it's the first thing I basically say to anybody: 'Hey, I'm Fiona. I've got HIV' ... Well, not exactly, but basically really quickly. As soon as I get an in to say anything, I get it in. Because that way someone can like me or not

and know my situation, you see? That way I don't feel in any way uncomfortable ... that way they'll know straight away ... They'll deal with it or they won't straight away. And I don't have to beat around the bush and buggerise around wondering, 'Can this person cope if I tell them?' I don't bother with any of that. I tell them and then *they* can deal with it or not.

Disclosure meant having to manage how the information was received and ... having to find ways to manage the boundaries and rules of disclosure once the secret was shared with others. These dynamics were often complicated by the lack of language and experience around HIV in heterosexual society.

Secrecy and disclosure were also shaped differently by social contexts. For those who belonged to relatively close-knit communities (mainly cultural, but also social, recreational, religious), the secret of HIV was often tenuous and permeable. Gossip and breaches of confidentiality were a regular source of anxiety. They often did not know who knew about their status and felt they had little control over that information. This sometimes made social interactions tense or awkward, and it was not uncommon for them to be questioned or confronted by members of their community. Audrey, 36, for example, said that, in her cultural community, people felt they had a right to know about her situation and that it was their responsibility to tell other people. She felt unable to trust anyone and was concerned other people might use the information against her or her children. 'It's a horrible situation to be in,' she said. 'It's like Chinese whispers.'

In some families, the secret of HIV was similarly porous. Some participants were unsure who in their family knew and whether members of their extended family had been told without their knowledge or consent. There was some discomfort around this, but also some understanding:

Most people, my guess is, they already know but they don't let you know that they know ... I've had that feeling from a lot of family members who weren't in the direct line of information, but word's obviously got out. Initially it made me angry, but by the same token I guess in a way it's human nature. It's information ... it affects them indirectly.

(Olivia, HIV-positive)

Much of the literature treats the act of disclosure as a kind of end point, as a matter resolved. In the interviews, disclosure emerged as an ongoing and complex process repeatedly up for negotiation (see Eribon, 2004; Sedgwick, 1990). Olivia summed up disclosure in the following way: 'It is difficult and it is always.' Disclosure meant having to manage how the information was received and subsequently revisited by those who were told. It also meant having to find ways to manage the boundaries and rules of disclosure once the secret was shared with others. These dynamics were often complicated by the lack of language and experience around HIV in heterosexual society.

There were many stories of having to take on the role of supporter, rather than supported, when friends or family members became distressed by the news. This sometimes took on an ongoing quality as participants felt continually called upon to reassure others that they (or their partner) were fine, sometimes to the extent that they felt compelled to withhold information or 'smooth things over' so as not to upset loved ones. The experience was often compounded for negative partners. Disclosing their partner's status to family and friends tended to open up a charged and irrevocable terrain of unspoken concerns and questions about not only their partner, but also their own well-being and HIV status. For Lucy, whose partner died a few years ago, this silent enquiry still made disclosure difficult:

I think one of the difficulties that I experienced in that role, too, was, and *still* is, strangely—I thought it would be over when he died—is that as soon as you say, 'My partner was HIV-positive' or 'My partner died of AIDS' or 'My partner has AIDS', as soon as you tell someone ... there's all these unspoken questions: 'How did he get it? Have you got it? Are you okay? Are you going to die? Are you not telling me something?' And there's a whole series of questions that are never spoken. So you feel you almost have to answer them, which is what happened when I told my family: 'Oh, by the way, I'm all right. I'm tested and I'm—' you know? So there's all this sort of stuff that you feel that you have to reassure people about, because they suddenly start to think, 'Oh, what's going on for her?'

Disclosure to family or friends did not always translate into support, nor did it mean that HIV was easily or regularly talked about. Participants found that those they had confided in often seemed reluctant to bring up the topic of HIV. While some welcomed this and spoke of it as liberating to be treated as 'normal', others were bewildered and unsure whether family and friends did not bring up the subject of HIV out of consideration or discomfort. Some described a more overt silencing of HIV in their families that arose out of uneasiness or disinterest, like an awkward spectre that could simply be wished away by not acknowledging it. Lucy spoke of her late partner Dylan:

It's interesting in my family, Dylan doesn't exist. He does *not* exist; he's an invisible person. He never happened. And I deliberately will say his name to try and make him a person who's part of our family history and my nieces actually are okay about that. But my generation don't want to acknowledge that he existed. So that's a sort of 'not in my family' thing. 'We didn't have this person in our family who was in a relationship with my sister,' or whatever, 'who was a drug addict who died of AIDS'. It just didn't happen. It never happened. And I think it's unconscious. I don't think there's a conscious, 'Ooh, that's all nasty!' I don't think it's like that, because they will all say, 'Oh, we are very open-minded, we've got all the right values, we vote left-wing,' et cetera, et cetera, but unconsciously there's just a rejection and I think that happens everywhere.

Disclosure also meant having to manage what happened with the information once it was in the hands of someone else. Confidentiality was often emphasised to the person to whom they disclosed, but a number of participants saw confidentiality as 'understood' and felt no need to instruct friends or family not to tell anyone. Others were more philosophical about confidentiality, in particular the women. They knew from experience that it was highly likely that people would tell someone else, even if asked not to. They recognised the need of others to talk to somebody, to have an outlet, and tried to factor that in when disclosing, negotiating with the person to whom they disclosed who that 'somebody' should be. Ellen, 43, explained:

Even though it's been scary, I've kind of felt that it wasn't fair of me to tell someone this *huge* thing and that they'd had to keep it to themselves, so I kind of did say that whilst it was in confidence and not to be bandied about, I understood that they had a need too, and I recommended that they talk about it too.

Partners and families

In building the micro-ghetto, secrecy became a shared and sometimes contested concern among its members, especially among those who were invested in the everyday management of living with HIV, here termed the 'HIV family'. The HIV family was a smaller cell inside the micro-ghetto, typically consisting of a couple and/or a few family members and existing clandestinely within a larger family unit of immediate or extended family. In this way, new and invisible family lines were drawn based on knowledge and confidentiality (see Spirig, 2002, for similar findings among HIV-affected families in Switzerland). Within the HIV family, the borders and rules of disclosure were either jointly negotiated by its members or more commonly seen as the implicit prerogative of the positive person. Claire, a negative partner aged 38, said:

It's his illness; it's not for me to go telling everybody. I just follow his lead; if he wants someone to know, he'll tell them. I don't take on the ownership of it ... I don't have it, I don't know what it's like to live with it, to be that sick, to have the drug regime and all the blood tests and all that basic stuff. I don't know what that's like, that's up to him, who he wants to tell. So we just leave it at that.

Disclosure was sometimes a source of tension in the HIV family, caused by conflict around control and around priorities of needs. This was most common among couples, with negative partners often wanting to disclose

I suppose he didn't want other people to know his private business ... he didn't want people to pity him ... So that was one of the reasons he didn't want me to tell people, but *I* wanted to.

to more people than did their positive partner. Isolation and a need for emotional support caused some negative partners to pressure their positive partner to disclose to family or friends against their will. This created stress and resentment on both sides, especially in couples where decisions around disclosure were seen as the right of the positive partner and where the negative partner had to ask their permission. In one couple for whom disclosure had been a major issue, the positive partner, Nigel, was disappointed that his spouse's expectations were not fulfilled after he eventually agreed to disclose:

I told a few people more so that Hazel could, you know, see people. But when you go to tell them, that's fine, it works out all right, but things don't come out of it, like what Hazel thought, that people would come and visit more ... And she wanted her family to know, so they could respond to it, you know? And they didn't ... At first after I told them, when things didn't happen, I felt, you know, all this pressure that I've had, you know, to do it. It's great they accepted it, but nothing else has changed, you know? But Hazel thought there'd be changes.

As HIV-affected people, and as key members of the micro-ghetto, negative partners sometimes felt that the boundaries and ownership of disclosure were far from clear-cut, or ambiguous at best. In the first few years of her relationship with Ethan, Stella, aged 42, disclosed with or without his consent (and sometimes knowledge) because she did not want to lie to her friends whom she regarded as understanding and as highly important people

in her life. This caused tensions between them and, years later, she felt more ambivalent about her right to make her own decisions around disclosure:

I tend to be probably overly open about issues with friends and there was always tension about who I would tell and who I wouldn't tell amongst my friends. So he used to get angry when I told people, but then I thought ... it's hard to explain why you do or don't do certain things, like why he wasn't working for a long time and why he ended up in hospital, all this kind of stuff is hard to lie about constantly. Ethan used to say that he spun elaborate webs of deception himself. But, you know, I wasn't as happy to do that. I suppose I was fortunate that most of the people I know are very sympathetic and didn't really care. There was no discrimination or fear. But Ethan was fearful. I suppose he didn't want other people to know his private business because he's very private and he didn't want people to pity him ... So that was one of the reasons he didn't want me to tell people, but *I* wanted to ... Sometimes I'd tell people and wouldn't tell him I'd told them ... I did begin to, I guess, feel ashamed or question my right or lack of right to tell people, as the years went by.

Less commonly, negative partners tried to persuade their positive partners to conceal their status, concerned that others would find out they had a relationship with a positive person. Angus, who lived a very public life with his HIV, ended a two-year relationship because he felt troubled by his partner's discomfort with his openness and by the seeming undercurrent of shame:

I was just totally amazed. It was not a problem with her. And I mean even to the point we had sex to a degree without a condom. There was not a problem, we were very careful and knew what was going on. But for other people to know, for friends of hers to know that she was with a man with HIV, oh, that was *not* on!

The rules of disclosure were sometimes a source of tension between family members as well, with parents or adult children trying to control decisions around disclosure or wanting to have a say. In the case of Antonio, a divorced 70-year-old man from Southern Europe, his daughter and son policed the secret of his HIV. Antonio wanted to include other family members in his micro-ghetto in the hope of getting more support, but his children explicitly disapproved. In his eyes, their injunction was not out of concern for him, but out of fear of being shamed in the small cultural community to which the family belonged. In another family, the mother was cautious about the disclosure of her young daughter's HIV, fearing her daughter would be stigmatised or discriminated against if people found out. Unbeknownst to her, her daughter

was 'out' among most of her friends and colleagues, all of whom were very supportive.

It is clear from the interviews that, when creating the micro-ghetto, disclosure to significant others entails a transfer of knowledge that can profoundly affect their lives as well. Ambiguity or rigidity around how to manage secrecy and differing needs can cause conflict or resentment. Positive people may feel disempowered and unsafe, while HIV-affected partners or family members may struggle to find legitimacy and recognition as people also 'living with HIV'. This suggests the importance of carefully and jointly negotiating the responsibilities, but also rights, of those who come to belong to the immediate HIV family inside the micro-ghetto, a process emphasised by Maria, who met her positive partner 15 years ago:

'We had to create a relationship with HIV ... We had to declare ourselves as a relationship to the world in a very structured and controlled way. We had to learn the rules between us about disclosure. We had to develop a language between us around HIV.'

This highlights the need for specific resources and support for negative partners and HIV families in the HIV sector. The availability of such resources is currently limited.

Concealment, 'passing' and dissociated lives

Participants had developed strategies to control information about their status to avoid accidental disclosure and to pass undetected in society. As Eribon writes, concealment of a stigmatised identity entails 'constant strategizing to avoid discovery ... a process of self-education, through a severe self-discipline that can never be relaxed, that must scrutinize every move, with the goal of appearing to be "as normal as everyone else"' (2004, p. 98). At home these strategies included hiding any telltale signs from children and uninitiated family members or when having visitors. Destroying printed HIV material immediately after perusal was also common: 'I get all the gay papers, read what's going on. As soon as I read it, tear them and throw them away. Anything that comes in the post, I read it or I hide it or I get rid of it straight away,' Antonio commented.

When dealing with the world outside the micro-ghetto, participants frequently assumed a different disease as a 'front', or used an existing illness as a cover to explain periods of ill health, hospital visits, medication or unemployment. This was particularly common among the men, many of whom struggled with a number of conditions, such as cancer, diabetes, neurological disorders, cardiovascular disease and depression. This

strategy freed them from feeling deceitful and from having to lie outright or keep track of fictitious stories:

Well, I've got other things that cover for it, see? I've got diabetes; I've got the cover of diabetes. I've had the trouble with the thyroid. I cover it with other things ... I've got plenty of things to cover it with. I've got the depression, I've got the thyroid and I've got diabetes and that keeps them happy. And I have all of them; I'm not telling lies about them; I have them.

(Morris, aged 58, HIV-positive)

This strategy was also common among negative partners who were invested in managing the secret of HIV and who had not only to protect themselves but also to cover for their positive partner. Claire tried to convince herself that her partner's health problems were really related to his cancer, not to his HIV, to avoid 'slipping up' when talking to others:

I'm *shocking* at telling lies. I'm a dead give-away! My face goes red and people *know* when I'm telling a lie. I've really got to think quickly. And, yeah, it's almost like you sort of have to create this fantasy and believe it yourself, to be able to pass it off. So I sort of try and think of the HIV as cancer and instead of calling it HIV I say 'the cancer', and technically I sort of look at it, okay; whilst he'll never ever be free of it or cured, it's remission. He still has to take medication to boost his immune system. Well, that's what medication for HIV is; it's to combat the problems in his immune system. So, yeah, I sort of put everything together and call it cancer.

A related strategy was to dissociate from HIV. HIV was often described as 'compartmentalised', as something kept absolutely separate from identity and from most aspects of life. Participants saw this as an inevitable consequence of keeping HIV a secret, but also as a conscious strategy to keep depression at bay, to get on with their lives and to facilitate the everyday process of 'passing'. Meagan, aged 45, explained:

In most normal relationships, the fact that I'm HIV-positive is compartmentalised and pushed away. It's not part of who I am ... I figure that the fact that I'm HIV-positive and I have dissociated it completely from my personality is not healthy ... I had to at the beginning. I had to make sure I didn't think about it. It was not across my consciousness at work because that would sometimes upset me ... I learned just to break it off so that I didn't think about it unduly. So, to me, that was a compartment. That's how I thought of it, as a compartment ... and that, I don't think, is healthy because it's like I am denying it's there, and it is there ... I think I did it first off for self-preservation because

I had to be able to function as a normal member of society rather than a disease-ridden hag, which is how I sort of viewed myself. So I had to learn to be able to put that aside and not consider it, and I had to do that so I could keep working. It's continued on.

As Meagan's account intimates, as much as they clung to 'normality', most participants found the efforts to manage secrecy and uphold a socially accepted identity demanding and transforming. In his work on the concealment of stigmatised sexualities, Eribon (2004, p. 99) conceptualises the effects of 'passing' in this way:

Such an effort at disguise, such an obligation to lie, even to those to whom one is close, to one's relatives, produces an 'intolerable' strain, which cannot fail to have profound effects on an individual personality, on a given subjectivity.

Participants commonly spoke of having become more guarded or cautious when interacting with others, having to watch what they said and how they said it and trying to

The hardest thing, I think, is the energy that it takes to maintain this two-lives thing of, 'I'm a person in the world and there's nothing different about me and then there's this other world I go home to every night.' It's like crossing through a passport check every day.

'suss people out' to ascertain whom they could trust. Some spoke of the difficulty of keeping up appearances when uninitiated friends, colleagues or family members talked disapprovingly of people with HIV. They used a number of expressions and metaphors to describe the experience of passing: 'living a lie', 'living behind a glass wall', 'not being all there', 'not feeling real', 'living in a bubble', and 'being deceptive' or 'inauthentic'. In Eribon's words, they lived 'dissociated' lives structured by a 'radical dissociation' between a presentable self and a self hidden from all but a few (2004, p. 104). Maria likened it to being a guest worker in the 'normal', non-HIV world outside the micro-ghetto:

The hardest thing, I think, is the energy that it takes to maintain this two-lives thing of, 'I'm a person in the world and there's nothing different about me and then there's this other world I go home to every night.'

It's like crossing through a passport check every day ... you're kind of like a guest worker there, you know, backwards and forwards across the border, except no one else can see the border. But *I* know everyday I go out to work I'm crossing the border out into the world where no one knows about the HIV. And everything I do or say has to be filtered through this, by now, highly automated filtration process, censoring process, which adjusts the image of me, and modulates it and tints it, so that I'm always presenting a picture to the world that is as closely as I can safely take it to the real thing, to keep the pressure off me.

Secrecy and 'passing' protect people from stigma and discrimination, but also preserve the illusion and privileges of normative heterosexuality. Many participants were aware of this dilemma. They recognised that their silence perpetuated the stigma of HIV and the lack of knowledge in the broader community about heterosexual people with HIV. But they pointed out that they were the ones who had to live with the potential consequences and few were prepared to take that risk (see Spirig, 2002). Claire, a partner, commented:

We've never really seen the need to discuss it with anybody else. And I know that doesn't help with the public perception of it, by keeping it secret, but it is self-preservation. The prejudices that they have; it's not worth running the risk. We don't want to lose our jobs, we don't want to face the stigmatisation that goes with it, so we just don't tell anybody. And as I said, it's not helping the great cause, but we have to live with that.

While the vast majority emphasised the importance of education to combat HIV stigma, only a few participants felt it was their role to educate the public. Some of the younger participants spoke of this, perhaps signalling a generational shift. Zoe, aged 24, for example, who was infected when she was 18, expressed a sense of responsibility to inform her peers:

They ask me questions, this and that, and I tell them. So at least they're getting educated as well. Like, because if you don't know, like, if you don't know anyone who has it, you won't know much about it, like, if no one talks to you about it, because I never knew anything when I found out [I was HIV-positive]. So I suppose they're lucky, they're getting someone to tell them what it's like.

The burden of secrecy that participants felt was evident in their experience of the interview. Many said they found the interview quite liberating, to be able to talk freely about their situation to someone who would listen and who would not judge them or violate their trust. It was revealing that several participants said they had never

spoken so much about their experience of living with HIV to anyone else before.

Sociality, isolation and intimacy

Secrecy shaped social relationships and friendships in profound ways. Social isolation was both a coping mechanism and a consequence of secrecy. The strain and alienation produced by leading dissociated lives often led to a withdrawal from social interactions or to a position on the sidelines of social and professional life. 'I lead a very quiet life now,' Morris observed. 'I don't socialise much. I definitely don't go out.' Many spoke of loss of friendships and intimacy, but also of consciously avoiding moments of intimacy to avoid having to push people away or having to 'abort relationships at a certain point', as Maria put it. Similarly, disclosure was a perceived threat to new, promising friendships, here described by Lucy:

I mean, *why* would I not want to tell my friend? You know? Why would it not be an easy thing to say to a friend, 'Oh, my partner died of AIDS'? I *fear* the rejection, I fear her seeing me differently, I fear her perception that 'Oh, I can't quite see her the same way now.' And that might all be irrational, but there's that kind of message out there in the community, for me, that it's not okay ... Yes, and so then you don't tell people because you think, 'I can't cope with it, I can't bear it. I just don't want the angst. I don't want to go home feeling miserable and thinking I've now lost a friend.'

These themes were particularly prominent among positive men, but also among female partners who not only had to manage their own stigmatised identity, but also had significantly less access to peer support than other people living with HIV. Female partners and positive men in relationships tended to retreat into the sheltered space of the micro-ghetto where they felt safe and authentic, while single positive men were often extremely lonely and overwhelmed by their HIV status:

I can't believe the way I'm living ... I just feel trapped by HIV/AIDS, trapped and isolated and miserable! ... It is hard living with it, but you learn to; you just learn to live with HIV/AIDS. Well, I have anyway. You learn and you persevere with it. You steer clear of things that you think will cause you problems, and that's relationships. I steer clear of them. I hate what I'm saying but it's a fact. That's what I do, you know? Because you've got to explain yourself and what's wrong with you ... Thank goodness I've got Fostel.

(Kevin, HIV-positive)

Isolation and loneliness were not central themes in the positive women's interviews. This does not necessarily mean that these experiences were absent, but may suggest a greater capacity to reach out for support or make meaningful connections with friends, family and peers. Indeed, in contrast to many of the positive men and female partners, several positive women reported having active social lives. For them, where HIV most often came into play was in the process of forming new friendships. Friendships were seen as an unfolding of an 'authentic' self through mutual sharing of confidences and trust. The inability to partake in such an exchange often evoked a sense of loss and intensified feelings of secrecy and separation, here voiced by Olivia:

I've talked to my husband about how it would be really nice to be totally open and honest with some of my new friends. It would be really great to not have to leave out huge chunks of my history when I'm talking about myself, if I really want to get to know somebody, if they really want to get to know me. A lot of stuff that's happening for me now has been impacted on by my past, so it's something that could quite easily come up in conversation ... Like people relate some type of experience to me about, you know, some difficulty or something ... that I can really relate to. But the reason I can relate to it is to do with my status, so I can't reflect that back to them, that I really understand where they're coming from ... I can't tell them that ... Normally you can relate to them and actually tell them a little snippet about yourself as well. And then they talk about themselves a bit more, you know, go back and forth. But I feel my bit sort of gets chopped fairly quickly. And they're not necessarily left with the feeling that I can relate to them or hear what they're saying.

Unwillingness to share the secret of HIV was not only driven by stigma and fear of rejection. It also arose from a widespread

sense that HIV was so alien in heterosexual society that it was impossible to share, that other heterosexuals lacked the necessary frames of reference to engage with such a life experience in a meaningful way. Maria explained:

I have disclosed up hill and down dale! And I watch people drift away ... What it's really about is *sharing*, because if you're going to have intimacy, it's about sharing something, and HIV, if you are straight, is an 'unshareable' thing. If you're gay it's shareable, but if you're straight it's not, because it makes you so *foreign*. In the straight world, HIV makes you so foreign. You might as well come from Mars. Suddenly—*splat*—you've sprouted green horns. You turn into something else because there's nothing in *their* life that will prepare them for it. There's no HIV competence generally in the community to prepare someone ... they can't come with me ... it's such an unusual and complicated 'alien-ness' that I would be educating them forever.

Only a few chose to socialise in the gay community, which was generally seen as more empathic. While this enabled them to 'come out' about HIV and create new friendships, it sometimes entailed another kind of 'passing'. Antonio, aged 70, avoided his ethnic community because of constant questions about his lack of a girlfriend or his refusal to remarry, an anomaly in his culture. Instead, he mainly socialised in inner-city HIV-positive gay communities, where he felt much more comfortable because it gave him privacy and support: 'They are very nice people and they look after you more than a straight person.' But while he was 'out' about his HIV status with his gay friends, he was not 'out' about his sexuality. Instead he pretended he was gay and was not prepared to tell them he was heterosexual for fear of jeopardising the friendships: 'Well, the little bit of friendship that is between us, I like to keep it going ... It's hard, but what can you do? I have to have some friends.'

4 Negotiating intimate relationships

HIV had a significant impact on relationships. Diagnosis contributed to the breakdown of the majority of existing relationships, while enduring couples struggled to adjust. In terms of forming a new relationship, participants faced the same issues that many people do: trust, intimacy, sex, compatibility, children, and how and where to meet someone. But these were all shaped by HIV in complex ways and compounded by additional issues around disclosure, transmission, illness, uncertainty and isolation (see Squire, 2003). How HIV shaped relationships was in turn shaped by stigma and by discourses of heterosexuality. Some participants found ways to negotiate these dynamics, but for others the difficulties posed by HIV were forbidding. There was also a

I think if I got into an emotional relationship and got rejected, that would probably destroy me ... It's easier not to have a partner ... I still have the idea that really I am damaged goods.

notable gender difference in the way HIV impacted on the participants' confidence and capacity to form relationships after diagnosis. Being single was much more common among the men. HIV Futures reported similar findings, with 38% of positive heterosexual men in regular relationships (Grierson & Mission, 2002) compared with 58.6% of positive women (McDonald et al., 2002).

HIV, gender and relationships

At the time of diagnosis, eight of the nine women were in a relationship. Four women had been infected sexually in that relationship. None expressed resentment towards her partner, primarily because all believed he had been genuinely unaware of his HIV status. Another woman was infected via needle sharing with her then partner and angrily suspected that he knew about his status. Of these eight relationships, six ended shortly after

diagnosis, primarily due to stresses caused by HIV. The two women who remained in their relationships were diagnosed at the same time as their partners. Today, one of these women is still with her husband, while the other woman's partner died of AIDS-related illness a few years ago. She is now in a new relationship. Seven women had entered into new relationships, with three women having had more than one relationship since diagnosis. At the time they were interviewed, three women were single, with one woman actively dating, two were in new or tentative relationships, and four were in committed relationships, only one of which pre-dated HIV.

Initially, few women thought they would ever have a relationship again and many felt a great sense of loss, believing they would have to relinquish their dreams of a family. Ruby, who was diagnosed in 2001, recalled thinking: 'Who's going to be in a relationship with me now?' Internalised feelings of pollution, shame and undesirability were common, as were fears of rejection and of infecting someone else. Even after many years, stigma and the risk of transmitting HIV posed barriers to relationships for two women in the study, Meagan, aged 45, and Fiona, aged 50, who were among the women who had been positive the longest. Meagan decided early on that relationships were out of the question:

I thought to myself, 'I'm never going to run the risk of infecting someone.' Then it became such an in-grown 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 think if I got into an emotional relationship and got rejected, that would probably destroy me ... It's easier not to have a partner. It's less confrontation ... I still have the idea that really I am damaged goods.

With time, counselling, peer support from other women and, in a few cases, a casual

romance, most women regained a sense of self-acceptance and confidence, opening up the possibility of intimacy. Now 33, Olivia recently married and was attempting to conceive. She had struggled with depression for years after her diagnosis at 18 and did, as she put it, 'a lot of work' on herself with the assistance of two social workers. After what she described as a long and hard process, she eventually 'found another way to be':

It was like, 'Forget it! It's all too hard!' ... My self-esteem was sort of rock-bottom and I felt pretty horrible about myself and everything else, so I wasn't capable of having a relationship really during that period. And besides that, it was just really, really scary and you've got to feel really okay about yourself ... 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.

While relationships were something that had figured in one way or another in most women's lives following their diagnosis, HIV was definitely a complicating factor for many, as Ruby said: 'It's hard enough to find somebody, let alone having the HIV on top of it.' At times, HIV compromised their choices and decisions. Some women said they had stayed in relationships longer than they probably should have and saw their reluctance to leave as closely related to underlying fears that no one else would want them. Yet, others had ended unsupportive relationships or relationships where sex was either absent or too problematic because of the partner's fears.

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On the whole, the women were generally more optimistic and active around relationships than the men, and several women had developed loving and supportive relationships since their diagnosis. The men's relationship patterns were quite different following diagnosis. While most women were in new relationships formed since diagnosis, four of the five men who were in committed relationships were all in the same relationship they had been in prior to diagnosis.

At the time of diagnosis, ten of the fourteen men were in a relationship. Two men were infected sexually in that

relationship. One of these men became distraught and ended the relationship, while the other man knew of his wife's HIV status and 'kind of expected it to happen'. His wife died of AIDS-related illness a few years later. Of the other eight relationships, three ended shortly after diagnosis, in two cases as a result of the man breaking the news to his partner. Five relationships continued. Among these, one man subsequently infected his wife, who later died. Another man had unknowingly infected his wife prior to his own diagnosis. Currently, nine men were single and five men were in committed relationships, four of which pre-dated diagnosis. Another five men had entered into new relationships after diagnosis, but four of these had ended, primarily due to HIV-related issues, including conflict over disclosure, difficulties around reproduction, or the partner being 'fed up with HIV'. Consequently, only one man in the study was in a relationship that began following diagnosis.

Both men and women feared or assumed that potential partners would reject them if they knew their status, but this was particularly common among men and often had more lasting effects on their attitudes towards relationships. They were also less inclined than the women to seek support and counselling to build their confidence around relationships. The men's narratives conveyed a strong sense of being compromised and undesirable as men. A service provider who was involved in starting Pozhet, but who no longer works in the sector, said this:

Well, one of the major issues I think for straight men and, to some extent, straight women, but I think more for straight men, are relationship issues. I think there's a major, major issue and from what I've seen in the time that I've been involved with Pozhet is this excruciating loneliness of straight men, that the difficulty of trying to negotiate a relationship with a woman is sometimes so insurmountable that they have said, 'I'm not even going to try. I've just decided that I'm not even going to make myself vulnerable in that way because it's too humiliating and upsetting and degrading to be rejected, to be made to feel that I'm not okay because of my HIV status.'

Gender roles may provide some insight into this. The cultural script of heterosexuality relies on particular models of masculinity and femininity based on power, sexuality and reproduction. HIV challenges both men's and women's capacity to enact conventional gender roles. For positive men, more than for positive women, these challenges include reproduction. Having children is an option available to many positive women today, but it is much more complicated for positive men and for their negative female partners. Thus HIV challenges heterosexual masculinity not only by raising questions around positive men's sexual orientation, but also by compromising their ability to father children and,

frequently, their physical ability to work and 'provide' as well, all significant tokens of dominant heterosexual masculinity in many cultures (see Connell, 1995).

These challenges were evident among both single men and those in relationships. Gavin, aged 46, who said his partner was initially attracted to him because she wanted 'a real man', lamented that HIV-related illness had since affected his ability to work and earn money, as well as his ability to have sex and to 'protect' his partner:

Nowadays I don't even *feel* like a man half the time, you know, I just feel useless type thing quite a lot. I can't do the things that I used to ... Really, you know, if we had been relying on sex and money, we would have been finished a *long* time ago ... I don't like travelling late night on trains anymore. When I was physically fit, it didn't worry me. Five years ago, if somebody had came up to me on a train and said, 'Hand over your wallet', I would have just dropped them there and then ... Now I can't do that and I don't want to put Katya at risk. I could protect her before; now I can't ... I don't ever want that to happen. It would make me feel pretty weak.

For many single men, these challenges to heterosexual masculinity conspired against the possibility of a relationship. Their desire to meet somebody to share their life with was often considered an impossible dream. They thought it would simply be too difficult to find a woman who would accept their HIV status, along with their compromised reproductive capacity. Many expressed a preference to find a positive woman. Reasons for this included mutual understanding and less difficulty around disclosure, sex and reproduction. But the chances of meeting a positive woman were seen as greatly reduced by a lack of meeting places for positive heterosexuals. Several men had placed personal ads in *Talkabout*, but with no success. Brendan, aged 46, said:

It's like they don't exist. I figured that the only way I'll get into a relationship again, or that part with a woman again, would have to be a chick that's positive because I can't see a, I'll use the word 'healthy', chick taking that fucking gamble. Because, unfortunately, once you get it, it's a fucking death penalty. It's just a matter of when.

Several men had made efforts to meet and date women, but some had given up after being rejected. A couple of men were having online relationships, one with positive women in the US and Africa. The other man had contact with Australian women through the internet, but had not disclosed to them. Some tried to keep their hopes alive in this way, but there was a general sense of defeat and sometimes outright conviction that HIV was a death knell for any future relationship. Kevin, aged 57, had not had a relationship since he was diagnosed nearly 20 years ago:

That's the main thing it's done to me; it's destroyed any relationship with a woman again ... Yeah, HIV has destroyed relationships for me, in forming one, because it's set in my head now that I just can't, you know? ... I fantasise sometimes and I have to stop myself; but it's just wonderful, the thought of meeting a lady, falling in love ... I've got to be careful I don't fantasise too much on that because the reality is, you know, I've got an insidious disease ... I don't think it's fair on a woman.

The men's pessimism about the prospect of a relationship was only partly borne out by the relationship patterns among negative partners. Four of the eight female partners in the study (six of whom were interviewed) had entered their relationship knowing their partner's HIV status. Most serodiscordant couples had met through work or social networks, avenues not always available to positive men who were unable to work or whose ability to socialise was limited by poverty or by depression. For many female partners, meeting their positive partner was a time of emotional turmoil. Perhaps indicative of the particular challenges facing heterosexual men with HIV, several female partners described how the men initially tried to push them away, afraid of the responsibility or afraid of emotional intimacy after being traumatised by their diagnosis. Maria described meeting her positive partner 15 years ago:

He was trying to get me to leave the relationship as much as I was trying to get him to come into it. And he definitely wanted to be in it, but he didn't know *how* to be in it ... the first years of our relationship were about me grappling with this person who had this *highly* stigmatised condition who'd been through a lot because of it in those early years and was very difficult to negotiate. He didn't realise how much he'd exiled from life. He had a whole different set of rules about work, about people, about relationships, he used drugs, you know, all of the stuff. He'd displaced his grief. He wasn't angry and he didn't act out, but he was unengaged. Because he had never dealt with it in a kind of structured way, he hadn't had any counselling, but it was so chaotic in those early years, no one knew what the hell was going on. The services weren't there.

It sometimes took a significant amount of time and effort to build these relationships, placing considerable demands on female partners in terms of commitment, but also trust on the part of the men. Claire said that it took her partner a long time to accept that she would stick around after he had disclosed to her:

For a long, long time, oh, probably a good twelve months, he kept saying, 'I'm waiting for the bubble to burst. I'm waiting for you to change your mind and call it off.' He didn't believe or wouldn't let himself relax and

believe that I wasn't going to just say, 'Okay, that's it! I can't deal with this.' And it took a long time for him to accept that ... he couldn't believe that I could accept it so easily and stand by him.

Of six male partners in the study (two of whom were interviewed), all had entered their relationship knowing their partner's status. While our study sample was too small to identify any definite gender pattern, the narratives of positive women and negative men meeting each other were quite different from those of positive men and negative women. The stories of negative female partners tended to be consistent with conventional gender patterns, with many female partners stepping into a caring, supporting or rescuing role (see van der Straten et al., 1998, for similar findings in the California Partner Study). The difficulty of recruiting negative male partners into the study prevents any easy comparison, but is perhaps in itself suggestive of a lesser involvement by these men in their partner's HIV-positivity.

The themes of lust and love featured in many stories of serodiscordant romance. In the stories of positive men and female partners, these themes were often juxtaposed with an emphasis on the need to negotiate the difficulties of HIV. In the stories of positive women and male partners, such difficulties were rarely articulated. Rather there was a tendency to play down HIV, to resist the positioning of HIV as a defining issue or as a potential obstacle and to instead describe it as inconsequential and irrelevant in the face of romance. Simon, aged 35, and his partner had been friends for several years before they started a relationship shortly after she was diagnosed:

It's strange. I mean, a lot of people sort of might look at it as a hindrance, but I never did. You know, I just saw Linda and it hasn't changed her any. I mean, she was a bit upset about it, obviously, and a bit ragged about it, but I don't know, it never sort of was a big stumbling block in my mind, at all. I don't know why that is, but it's just the way it was, and it still doesn't bother me, so it's just something we've got to work around.

Issues such as infectivity and the impact of HIV on gender identity are likely to shape how stories of serodiscordant romance are told. With transmission being eight times more likely from male to female, the implications faced by negative female partners are quite different from those faced by negative male partners. Also, HIV does not affect negative male partners' health, body shape, or ability to reproduce, work, provide and protect, as it may do in the case of positive men. These differences have different implications for positive women and for female partners. Negative female partners are not only at more risk of infection through sex than negative male partners, but may experience multiple losses, such as not having children

or, if their positive partner is sick, financial insecurity. In such a case, they may have to take on the role of provider, or else the role of carer, which may affect their careers and sense of social connectedness, all of which add to the difficulties of concealment and disclosure vis-à-vis the outside world.

Disclosure to sexual partners

Disclosure to a sexual partner emerged as a significant and difficult issue in the interviews. Two forms of disclosure were described: disclosure to an existing partner and disclosure to a new or potential partner. Firstly, many single participants viewed disclosure to a sexual partner as a fraught and terrifying decision, sometimes posing a major obstacle to even *trying* to find a relationship. Not only did it bring up the participants' own feelings around being

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 ...

positive, but it also involved having to deal with another person's reaction. For many, women in particular, being able to *trust* their potential partner was a prerequisite for even contemplating disclosure. This is how Donna, aged 47, 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'? ... 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 out how they will react. For me to even tell them at the beginning, 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.

Most participants 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 et

al., 2005, p. 10). This assumption disregards the cultural complexities of sex, romance and gender power relations, and the many valid reasons for individuals *not* disclosing their status, including stigma, fear of rejection, gossip and violence.

Disclosure to sexual partners is also complicated by the invisibility of HIV among heterosexuals. In the heterosexual encounter, HIV is an anomaly; it is alien and unanticipated, and people with HIV are often imagined as sexually deviant in some way, or as having no right to a sexual life. Faced with this, how do you disclose the totally unexpected, the unthinkable, and then manage people's ignorance or fear? Heterosexuals with HIV may themselves be unfamiliar with the process of disclosure and with 'coming out', 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 et al., 1997, p. 11). This was evident in many stories. Zoe, aged 24, 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 all right 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 difficulties of disclosure were acknowledged by many partners in the study. Several said that they themselves had had to initiate or force the act of disclosure when they began to realise something was amiss. Jason, aged 23, found out about Audrey's HIV status through gossip in their close-knit cultural community after they had had sex:

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. I was saying to her, you know, 'I wouldn't have cared if you'd just told me. That's just the kind of person I am. I don't care.' But she's, you know, 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.

While the partners in the study obviously did not reject their HIV-positive partners after disclosure, some were upset about the manner in which it happened. Claire, for example, was understanding of her partner's fear of disclosing, but felt deprived of her right to make her own decisions when he disclosed only after they had been in a sexual relationship for some time:

That's what made me angry with [him]. He *had* it and he didn't tell me. To me, that's just, hang on a minute, don't go having sex with somebody and not telling them. That's not your choice to make, whether they take that risk or not. That's probably my only big beef about it with him ... I did tell him at the time. I said, 'Well, hey, you should have told me ... It would have helped and explained a lot of things.' But what's done is done; now I know, let's get on with it, and start dealing with it. So I sort of let that go.

As these accounts suggest, the *timing* of disclosure to a sexual partner can be a particularly difficult decision to negotiate. Disclosure may require a degree of intimacy and trust, but how do people develop an intimate relationship in the absence of emotional and sexual intimacy? Participants struggled with the dilemma of whether or not to tell straight away and risk being rejected and also risk gossip, or whether to wait and see if the relationship developed into something more serious and *then* disclose, in which case rejection could be devastating because of greater emotional investment. If they waited to disclose, the partner might also get upset or angry that they had not been told earlier, especially if sex had already taken place. Or they might feel emotionally deceived, opening up irreparable issues of distrust.

Participants used a range of approaches to disclosure, such as 'always disclose', 'do not disclose and rely on condoms', 'do not disclose and have non-penetrative sex' and 'avoid sexual relationships altogether'. Although not reported by any participant, there is obviously a fifth approach, which is to not disclose and not use a condom. Many expressed fears about the legal implications of failing to disclose HIV to sexual partners, particularly in the context of unsafe sex, and several participants cited media reports of such cases. This may have inhibited their willingness to discuss any personal practice of this approach, other than as an accidental incident.

A number of men and women said they would always disclose to sexual partners. Olivia felt it was important to disclose prior to sex, not out of legal obligation so much as out of a sense of ethical responsibility, but she 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.

Several participants who took this approach relayed good experiences, both with casual partners and with

budding romances, many of which turned into committed relationships. Tobias, aged 51, said of the woman he subsequently had a seven-year relationship with: 'She didn't bat an eyelid. She just didn't change. She was incredible, absolutely incredible.' Similarly, Donna said of the man she went on to have a sixteen-year relationship with: 'He did not care at all, did not care *at all*, except that he was sad for me. He had no concern for himself whatsoever.' For some, the relief and elation of a good response caused them to enter into a relationship or marriage 'for the wrong reasons', as Evan, aged 43, put it. Experiences of rejection were also common, especially among the men. This might have been because they sometimes disclosed more readily than the women, but often with little preparation or skill. Antonio, aged 70, had disclosed to several women: 'You can see the change in their face when you tell them that you are HIV ... Yeah, once you tell them, that's it. Hello and goodbye'. After an initial rejection, Brendan, aged 46, experimented with the timing of disclosure:

Well, I was trying to figure out how to get around it because, eventually, no matter where in the proceedings, there comes a time when you have to discuss it. I cannot go to bed with a chick without telling her ... I've had two experiences with it, [but] the discussion of the HIV seems to kill it ... With the first one I waited until I started to get to know her. And then, of course, it was coming to that part and I thought, well, I'd better tell her and that was the end of that. And the other one, I thought, 'Well, fuck it, I'll just drop it on the table straight away. That way I don't have to worry about all the fucking drama later on', and lucky I did, because she went straight away.

A number of participants relied on safe sex to counter what they saw as an unreasonable obligation to disclose. They believed it was acceptable *not* to disclose as long as they did not put their sexual partners at risk. Derek, aged 56, for example, had engaged in non-penetrative sex with women without disclosing. After being traumatised by the reaction of his former partner when he disclosed shortly after his diagnosis, he decided never to disclose again: '[She] went so berserk that, I mean, it just put the fear of God in me telling anybody else, ever, about it.' These participants insisted on their position as responsible subjects by emphasising that their sexual partners were safer with them than they probably would be in any other heterosexual sexual encounter. 'I'm protecting them totally so I don't believe that I'm doing anything wrong,' Derek explained. 'My own conscience is clear on it.' Similarly, Rowan, aged 51, said: 'My bottom line is I protect my partner.' Unless a relationship appeared to have some long-term prospect, few were prepared to disclose, as Donna explained:

I have dated men that there's no way in the world I'd tell. No way! Not because they wouldn't be accepting, but because why would I tell them? I don't want to have a long-term relationship with them ... 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 always an easy option. The lack of HIV awareness and a safe-sex culture among heterosexuals often complicated the matter. 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 heterosexuals must renegotiate some of its meanings 'and cannot rely on the other participant in the encounter ... to share their understanding' (Crawford et al., 1997, p. 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 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 (see Moore & Parker Halford, 1999; Crawford et al., 1997; de Visser, 2005; Kippax et al., 1994).

These dynamics were difficult to negotiate for both men and women. The specific gender dynamics of heterosexual sex often gave the women less room to negotiate, while some men felt that women were puzzled, sometimes offended, by their persistent condom use or their avoidance of penetrative sex: 'They probably think, "There's something seriously wrong with this chap,"' Derek commented. 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 unprotected sex without disclosure had occurred, there were considerable emotional upheaval and self-blame.

Only one participant did not disclose to a sexual partner who subsequently became a spouse. It was only after intervention by mutual friends four years into the marriage that the partner became aware of her husband's HIV status. While this seems unusual, one UK study with positive heterosexual men found that 10% of the study sample had not disclosed to their regular partner (Sherr & Barry, 2004).

Whatever their approach, the lack of hard and fast rules for disclosing to sexual partners, along with the foreignness

of HIV in heterosexual encounters, made each particular situation a complex and unique experience, rather than a matter of rational choice and routine. However, some participants, particularly the women, emphasised the importance of carefully preparing 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

Many partners emphasised the importance of information and communication in the process of coming to terms with their partner's status. Being invited into the emotional world of their partner was seen as imperative ...

rejection, but because the partner might react with a range of emotions or questions and be in need of emotional support. This approach was often the more successful one, which highlights the importance of appropriate resources being available both to heterosexual men and women who disclose, and to the sexual partners to whom they disclose.

Disclosure to a spouse is different in that it occurs within an existing context of presumed intimacy and trust and may therefore raise painful issues around transmission, such as undisclosed drug use, sexual infidelity and, in the case of positive men, sexual orientation. Several positive men in the study had experienced this situation and two relationships had ended after disclosure, one in which infection was the result of the positive man having been, as he put it, 'a naughty boy'. But in most cases it was possible to establish that the men had been positive unknowingly for many years and had likely been infected prior to their marriage or current relationship. Even so, most men expected their partners or wives to leave and believed this would have been a legitimate and understandable course of action. They were generally quite surprised that their partners stayed, and questioned whether they would have made the same choice had the situation been reversed. As Gavin said:

Yes, I expected her to go, straight away. I thought, 'Well, she's going to leave me now.' And, even if she's got it herself, she's going to leave me because I gave it to her and, if she hasn't got it, she's not going to want to hang around and I wouldn't have blamed her. I don't blame people for being scared; it's because of the education

they got ... I don't know if I would myself. I didn't think she'd want to stay around because, you know, who really wants to have a husband or boyfriend who's basically going to be useless to do anything anyhow.

Issues around transmission were not raised by any of the partners in this study, but most who had experienced disclosure in an existing relationship revealed initial moments of doubt about whether to stay. Love and loyalty were frequently invoked in partners' decisions to stay, as were concerns about the positive partner's welfare and support should they leave. Claire and her partner were colleagues for many years prior to starting a relationship. He did not disclose to her until well over a year after they had moved in together. While upset about his belated disclosure, she felt the relationship was too valuable to walk away from and decided it would work if they were practical about it and open with each other:

My attitude at the time was, well, we were too far down the track in our relationship to say, 'Hey!' I felt that I couldn't live with myself just saying, 'Oh, forget it!' ... We were very, very close ... And I just don't walk away from those sorts of things. I mean, okay, it's there; we deal with it. And that is what I said to him, 'Well, okay, now I know, what do we do about it? What impact is that going to have on me, my kids, and how do we deal with this? I know we can't cure it, we can't fight it, but how do we live with it?' And we then spent the rest of the day talking about it ... He kept sort of, if I had questions, he would answer them and he'd talk to me when I wanted to talk to him about it and he sort of asked if I wanted to see a counsellor or anybody, he could make arrangements for that ... He's been, ever since then, very patient. He's given me as much literature as he can get his hands on to find out about stuff. I go to all his doctors' visits with him ... he lets me deal with it at my own pace ... It's not something that I wanted to happen or be involved with. It's not something that you'd ever think, 'Oh, yeah, wow! This is going to happen.' *But* it's there; you deal with it.

Many partners emphasised the importance of information and communication in the process of coming to terms with their partner's status. Being invited into the emotional world of their partner was seen as imperative, as was their sense of being legitimate participants in 'living with HIV'. The attainment of this often depended on the existing communication patterns and emotional intimacy in the relationship, highlighting the fact that couples who are not resourced in this way may require external support in the form of specialised counselling or other programs. However, the availability of these services for heterosexual couples affected by HIV is limited.

‘Sero-sharing’ and ‘sero-silence’

HIV figured in diverse ways in serodiscordant relationships, but was generally located somewhere along a continuum between two distinct modes of living with HIV as a couple. These modes, which are discussed below, are conceptualised here as ‘sero-sharing’, in which HIV was a shared experience, and ‘sero-silence’, in which HIV was less so. There was no obvious association between these modes and disclosure to an existing or new partner. However, illness experience played a part. The study sample was too small to draw out any distinct age or gender patterns. Positive men and negative female partners tended more towards sero-sharing, but it is difficult to ascertain whether this was indicative of gender differences or due to the fact that more positive men had experienced HIV illness than had positive women.

In sero-sharing relationships, both partners were engaged in the everyday emotional and practical management of HIV in various ways. There was a sense of shared experience, of a shared identity as an ‘HIV couple’. HIV was often described as a bond between the partners: ‘It’s something that locks us together ... It’s something that we have that’s just ours. We understand each other,’ Claire said. Negative partners were typically well informed about HIV and HIV was freely and openly discussed in the relationship. These couples were often extremely close and devoted, but often isolated, with the partners relying on each other for companionship and support. Gavin said about his partner Katya: ‘She’s lost a lot of friends. I’ve lost a lot of friends. Basically we care about each other a lot. We look after each other.’ Maria elaborated:

Our life together is a very particular life; it’s a consciously nurturing life and it’s full of rituals ... rituals around the fact that we are still together, that we love each other, that we’ve survived, that every day is a precious time and it’s still precious ... We don’t have to do anything extraordinary; it’s just that we live *knowingly*. Because time and each other is all we’ve got in life and we still have that and I feel so blessed, I can’t tell you. If everything left me in life and he was still here, I would feel blessed. He survived the plague of the twenty-first century and I don’t ask life anything more. I have been given the thing I didn’t expect, I never asked for; I didn’t hope he would live. He has!

Many of these couples had been through a lot together. Often the positive partner had been extremely ill or near death, shaping the lives of both partners in profound ways. Grief and suffering forced HIV into focus, making it ‘real’ as a shared concern and experience. Likewise, ongoing uncertainty affected the identities and life ambitions of both—their choices around work, career, friendships,

children—and changes in the epidemic forced them to reinvent themselves and their relationship together. Maria commented on the introduction of combination therapy:

I had to reinvent as someone whose partner’s not dying. That transition from the wife and widow-to-be to the wife in normal times was very hard. It took me a couple of years to undo all the practices and habits of thinking that I had built up, a lot of them consciously, over the years to deal with his death and to deal with HIV.

In sero-silent relationships, HIV tended to be much more in the background. While there were exceptions, this mode was more common in more recent relationships or in couples who had not endured serious illness or suffering. In this mode, HIV was often seen by either or both partners as the domain of the positive partner rather than as a shared experience. Negative partners were rarely involved

In part, silence around HIV in relationships reflects the general silence around HIV in heterosexual society.

in the medical or emotional management of HIV or in decision-making relating to the virus. They were generally less informed than negative partners in sero-sharing couples and HIV was not often talked about in their relationships. In some couples, HIV was not discussed at all. Jason described how HIV figured in his relationship with Audrey who was currently well and on treatments:

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. We just live our life ... No, we never talk about it. We argue about other things, but we never talk about this, because there’s too much going on in life, because this is like minor ... I don’t know about Audrey. It might be a big thing for her. But for me, because I love her, I don’t really give a damn ... It’s never an issue. Not at all. No, I don’t want to talk about it. I mean, like as in making it an issue. I don’t want to make it an issue. But, you know, if she wants to talk about it, she can talk about it. But I don’t want to bring it up.

Some participants (including Audrey) welcomed the fact that their partner did not make an issue of HIV. They spoke of this as liberating and supportive, as a sign of their partner’s unconditional acceptance, while others recognised that their partner might 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, their

refusal to engage with it, even after many years. Some found it difficult to talk to their partner about their fears of infecting them or about the underlying stress of their partner's essentially *unknown* serostatus most of the time. Others felt there was little sympathy for the effects of HIV or treatments on their ability to do things. Donna described this invisibility of the virus in her previous relationship and how acceptance could 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.

Conversely, some negative partners felt excluded from any emotional and practical engagement with their partner's HIV: 'It's like we're two different people, not a couple,' Hazel stated. One partner, Simon, struggled to create a sero-sharing relationship. He felt his partner was not able to communicate her feelings about being positive to him: 'She knows I don't have a problem with it; it's just that *she's* got a problem, she finds it hard to deal with.' His partner, who sat in on the interview agreed: 'Yeah, I've got the problem with it, not him ... I'm just blocking it out, not wanting to deal with it at the moment, yeah.' Simon 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.

While silence around HIV enabled a comforting sense of normality for some couples, it was a source of tension for others. In part, silence around HIV in relationships reflects the general silence around HIV in heterosexual society. But it also signals the general absence of peers, role models and community among those who live heterosexually with the virus, resources that are essential to the production of a language around HIV (see Chapter 5).

Sex, sexual strategies and testing

HIV shaped the participants' sense of themselves as sexual beings in significant ways. Testing HIV-positive was commonly experienced as a loss of sexuality and most believed they would never have sex again. Many perceived themselves as 'damaged goods' and feared rejection from potential partners. In addition, HIV introduced a sense of threat into sex, which centred on fears of infecting

somebody else (see Keegan et al., 2005). While this became an entrenched reality for some, many participants had resumed sexual activity at some point since their diagnosis. Ellen, aged 43, described her first sexual relationship after diagnosis:

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.

At the time of interview, fewer than half of the participants were sexually active, including four of the fourteen men, five of the nine women and five of the eight partners. In comparison, the Australian HIV Futures study found that around 50% of the positive men and 65% of the positive women they surveyed were sexually active (Grierson et al., 2004). Similarly, a UK study with positive women found that 62% were currently or had been sexually active since their diagnosis (Keegan et al., 2005). In our study, some participants enjoyed a good sex life, but others experienced a number of HIV-specific barriers to sex, including external and internalised stigma, difficulties around disclosure, ill health, depression, impotence, fatigue, body shape change, social isolation and fear of transmission. Several general barriers were also mentioned, including ageing, being a single parent, and lack of financial or social opportunities to meet sexual partners.

Sex for single heterosexuals with HIV is very different from sex in the positive gay community. Generally speaking, heterosexual people, unlike gay men, are not politicised as a sexual community and do not have a history of progressive, innovative and negotiated sexual practice (Segal, 1990, p. 164). There are fewer opportunities to meet casual sexual partners, there are no sex venues where positive heterosexuals could meet and there is no culture of HIV-positive sex. The lack of a safe-sex culture among heterosexuals is another complicating factor (see discussion under earlier heading 'Disclosure to sexual partners'). Because of these limitations and the above-mentioned barriers, casual sex was quite rare among those who were single. Only one woman had casual sex and, of the two single men who had casual sex, one paid for sex:

My sex life these days is basically, every now and then I go to the parlours, you know. And I'm honest there, you know, well, honest in the sense of a condom. But it's a touch thing with me, you know? ... It's not the answer, but sometimes it's one way that I can—I admit it, I like to feel good, you know. I'm human.

Several men and women who were single had resigned themselves to never having sex again. For Morris, who was diagnosed in 1998, a sexual relationship was 'out of the question completely'. Fiona, who was diagnosed 15 years ago, remarked that HIV had had 'a massive impact' on her life, 'because it means I can't have a man in my life'. Though missing the intimacy, 'the cuddles', she was adamant that she did not want to have sex:

Well, the point is I couldn't take the risk ... 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, you know. So that's it, yes, it's really a big impact ... I just couldn't live with it, love, if I gave someone that disease. That's me, whereas other people, well, good on them if they can.

Barriers to sex were also found among couples, but there was a notable difference between couples who had entered into a relationship with the knowledge of HIV and those who had not. Couples who had met following diagnosis tended to enjoy an active sex life, while sex was much less common where diagnosis had occurred in an existing relationship. Issues of choice are likely to play a part in this difference, with couples who got together following diagnosis having entered into their relationship with prior knowledge of HIV and with a sense of their sexuality and identity that might be very different from those who had had to deal with the upheaval and losses of a diagnosis in an existing relationship.

Other factors also came into play. In all couples who were already together at the time of diagnosis, the positive partner was male and often a later presenter. Ill health, depression and impotence were cited as primary barriers to sex, although fear of infecting a partner was also mentioned. The loss of their sex life was often a distressing experience. When Gavin, aged 46, became impotent due to HIV-related illness, he and his partner Katya tried a number of strategies, such as Viagra and Caverject, to no avail: 'So basically that was sex gone out the door completely. That upset *her* quite a lot and it upset *me*, because I couldn't do nothing about it ... Also, the fear of infection; that was another thing.' Loss of sex sometimes became an ongoing source of tension in couples, also challenging the gender identity of negative female partners, who felt hurt and deprived of their sexuality, especially if there was little communication or a perception that the positive partner was indifferent to their feelings:

The relationship side of it, HIV stopped that. And that's not being a couple. That's a big one! One day [sex] just stopped like that, so that was the HIV. Yeah, that's the biggest one ... And I didn't get a say in it, either ... He didn't want to know about it. He said, 'Oh well, that's it.' ... He doesn't want to discuss it. Every time I bring

it up, he says, 'Oh no, no' ... In the beginning I was very angry and hurt, because everyone likes to, you know, if you've been married that long ... But I think it's been going on too long now that I don't think about it. Every now and again I do; I think, 'Oh, what's in it for me?' You know? But that's what marriages are about, you know. You take the good with the bad, but I just think it was a big bloody catastrophe.

(Hazel, HIV-negative partner)

Conversely, positive male partners struggled with feelings of guilt because they felt responsible for the loss of sex in their relationship. For them, sex became a source of stress and confusion as they tried to juggle their own sexual difficulties with the sexual needs of their partner, causing some to avoid any physical or sexual contact altogether. Nigel, aged 54, explained:

Sometimes I'm not sure, like things are coming together and then I think, 'Oh, is it going to go too far?' or I don't want it to go over into the full thing because I don't have it in me. So she's always said, 'Look, there's petting and all that sort of thing.' But I know then sometimes if I start, she wants more. And that's been a big conflict. And I know her feelings, too, because she's still sexually, you know, capable and all that sort of thing. And we have, earlier times, we still had intercourse with precautions and that and she got used to that. But then, after a while, I just couldn't. I'd start off all right but just couldn't stay there and, you know ... I mean, it just affects—I dunno, mentally and the drugs and probably the mental part has affected everything ... But I've made the effort to give more hugs and be a bit more affectionate in that way ... I mean, she doesn't look for it as much now. But it has been an issue; yeah, it has.

Couples who were sexually active were mostly relatively well informed about safe and unsafe sex. However, they used a variety of strategies to manage the tension between sexual risk and sexual desire, and unprotected sex was quite common. Overseas studies estimate that 25% to 45% of sexually active serodiscordant heterosexual couples engage in unprotected sex (Buchacz et al., 2001; Skurnick et al., 1998; Lansky et al., 2000; Semple et al., 2002). Any discussion of sexual strategies among serodiscordant couples needs to be understood in the context of heterosexual transmission of HIV. The California Partner Study, a longitudinal study with serodiscordant heterosexual couples, estimated that there was a nine in 10000 chance of an HIV-positive man infecting a female partner in any instance of unprotected sexual intercourse. Female to male transmission under the same circumstances was about eight times less likely. Unprotected sex, anal sex and the presence of another sexually transmitted disease were found to be strong predictors of transmission (Padian et al., 1997).

In terms of gender dynamics, there is a paucity of studies examining sexual strategies and gender differences among serodiscordant couples. What literature there is provides conflicting information. A UK study with positive women found that all sexually active women were committed to safe-sex practice and that very few described incidents of unprotected sex (Keegan et al., 2005). However, a US study found that unprotected sex with a negative partner was more common among positive women than men (Semple et al., 2002, p. 50). In several studies with positive women, partner refusal was the primary reason for not using condoms (Clark et al., 1997; Cranson & Caron, 1998; Hankins et al., 1997). Yet, 'a significant percentage of HIV+ women also reported that non-condom use was a mutual decision motivated by the long-term, committed, and monogamous nature of their sexual relationship' (Semple et al., 2002). In contrast, the California Partner Study found that 'consistency of condom use did not depend on the gender of the HIV-infected partner or duration of sexual relationship' (Buchacz et al., 2001, p. 289). This study also found that negative partners were often more willing to take sexual risks than their positive partners (van der Straten et al., 1998).

Our study sample was too small to draw out any gender differences, but we identified a number of approaches to having a sexual life, which included strategies for managing the risk of transmission. These included: penetrative sex with a condom; penetrative sex without a condom, or penetrative sex without a condom but with withdrawal; unprotected but 'gentle' sex (no 'rough' sex, no anal sex, no breaking of skin); no unprotected sex during menstruation; an ongoing struggle to use condoms all of the time; the absence of a negotiated and structured approach to sex; and all of the above at different times. In addition, positive partners either took responsibility for sexual strategies, or left the responsibility for deciding on a strategy to their negative partner (see van der Straten et al., 1998, for similar findings).

Just over half the couples used condoms consistently as a firmly integrated part of their sexual practice. This choice was not always uncomplicated, especially for positive partners whose allegiance to condoms was obligated by profound fears and feelings of responsibility, but was incompatible with their ideas of intimacy and romance. Olivia, who recently married, made it a rule always to 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:

Sometimes I just want to blow up all the condoms in the world ... 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 ... I have this sort of conflict in my head a lot about, you know, I'd really like to have unprotected sex and I know logically that it's pretty unlikely that he would seroconvert, because I've been undetectable for four years and that. But because there is a slim chance, I'd be terrified.

Some couples adopted a range of alternative strategies to reduce transmission risk. They rarely used condoms and instead relied on undetectable viral loads, withdrawal or the practice of 'gentle' sex. These strategies were seen as reasonable, rational precautions against the risk of transmission in the context of current knowledge, and were also closely linked with notions of intimacy and with the positive partner's sense of being accepted by their negative partner. In these couples, the notion of responsibility was often more dispersed. The positive partners, in particular, resisted discourses that placed responsibility squarely on the positive partner and robbed the negative partner of responsible agency in sexual decision-making. 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 sexual abstinence during menstruation. She also emphasised that it was her partner who *chose* to have unprotected sex; that the decision was *his*. 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.

Being pressured into unprotected sex by their partner was an issue not raised by any of the participants. By all accounts, condoms were dispensed with only if both partners were comfortable with doing so. This included couples with both male and female negative partners. But some partners' accounts were deeply ambivalent. Claire reflected on the risks she and her positive partner were taking in order to stay sexually active, and rationalised that risk-taking was a part of life:

Every now and then I sort of think, 'Oh, we should be more careful', because we're not terribly careful. We don't use condoms and, while we don't have sex an awful lot—usually we're too tired or there's just not the opportunity—sometimes I think, 'Oh, we should use a condom', but I hate them. They're fiddly; you lose the moment. So we just don't. He's very good with his

withdrawal method ... Oh, every now and then you get a little bit of a 'God, I'd hate to get that'. You just see what he goes through and I don't know what I'd do if I ever got that. Yes. I don't, I don't know. If it happens, it happens. I've met enough people to know that you can live with it; it's not a death sentence necessarily. But it's not that you sort of think, 'Oh well, yeah, okay, I'm likely to get it.' You just don't want it. *You avoid it at all cost. But you do take risks ...* and so does everybody else. The number of people that don't use condoms, when they're in a heterosexual relationship, it's quite surprising; that they're prepared to take that risk.

For some couples, unprotected sex was not a conscious strategy. Rather, condom use was their intended strategy but they struggled to implement it. This was particularly common among couples who had recently met, and for whom decisions and communication were often compromised by the vicissitudes of new love. Mahmoud and Amy had mostly had unprotected sex since they met a year before the interview and Amy had recently become pregnant. Their doctor told them that the chances of Amy being infected were small because of Mahmoud's undetectability. But he cautioned them to start using condoms as Amy's pregnancy made her more vulnerable to infection. Mahmoud said it would 'destroy' him if Amy became infected but, despite good intentions, they continued to have unprotected sex every so often:

Yeah, sometimes we don't think, just not thinking, you know. Afterwards, we say, 'We can't do this anymore; we must use a condom,' and we'll say, 'Yeah, yeah, yeah'. And the next time comes along, and we go into a different world, you know? It's not—yeah, we've taken a lot of risks.

In some relationships there was no negotiated sexual strategy. Rather, sex was presented as an unproblematic event that simply 'happened'. In one such couple, both partners said that they mainly had unprotected sex and only occasionally used a condom. Neither could articulate how or why they made these choices and neither spoke of it as being an issue. The negative male partner 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 denial of HIV. But it also hints at the lack of a language around safe sex among heterosexuals and 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 et al., 1993b). This suggests the importance of developing specific resources for serodiscordant heterosexual couples that not only take into account gender differences in barriers to condom use, which have been identified in other studies, but also encourage the idea and practice of positive heterosexual sex as pleasurable, negotiated and safe. Simon, a negative partner, hinted at this in the following extract where he explained that the thought of HIV did not interfere during sex, partly because of a conscious, structured approach, and partly because sex was a designated space of pleasure:

No, no way! Not when you're *having* sex together. Maybe ten minutes after [laughs]. But no, not really ... No, that doesn't come into my mind either. I mean, you've got to know what you're doing prior to doing it and while you're there too. But no, it's just not a problem at all ... You can't, otherwise it wouldn't make the moment right then, would it? You're supposed to be forgetting your worries for however long it goes for [laughs].

Positive partners' fear of infecting a negative partner was a much more common theme in the interviews than negative partners' fear of *becoming* infected (see van der Straten et al., 1998). This was true for both men and women. It is possible that this theme was played down by negative partners out of bravado or a sense of loyalty

I found eventually it got to the point where I had to say to [partner], 'I don't want to have sex for quite some time. I *need* to know if I'm negative. I've lost the plot. I want a test that is truly negative.'

to their partner. Indeed, many negative partners were quite fatalistic—'if it happens, it happens'—and explained that, while they did what they could to ensure they did not get infected, they did not want to live in fear of the eventuality. Simon, for example, commented:

I'm not scared of it, but it doesn't mean that I should be—it doesn't mean I'm blasé about it. I mean, yeah, I've obviously got to be careful because there's no use in both of us being sick. But if that happened, I mean it wouldn't be the end of the world. For me, anyway, I think she'd have a different attitude to it than I would but, yeah. I don't have a real big problem if it *does* happen, but it's not that I'm chasing it, though, definitely not. But I'm not scared of it ... If I was scared

of it, I mean, we couldn't have a proper relationship at all. That wouldn't make much sense. There's no use in me being here if that was the case.

Where fears about becoming infected were expressed, it was more commonly by female partners. Stella, aged 42, said that she was sometimes fearful at the beginning of her relationship, but the fear lessened with time and experience:

Early on I used to get quite, every now and then, I used to get very anxious and tense about it and fearful about whether I'd get the virus. Then I just worked out the best thing to do was to have a test. But, on the whole, after so many years I figured that it must be pretty hard to get and I think, over the years we'd mastered the technique of, you know, using condoms properly so they wouldn't break, so I wasn't very disturbed about it, or fearful ... I mean, I haven't had a test *now* for two years so I still can't talk. I can't say for sure I'm definitely not HIV-positive at this moment.

In sexually active serodiscordant couples, sex is a portal of potential identity change for negative partners. 'A little bit of rubber is between you and another identity,' Maria observed. 'It's *very* mind-whirling.' As Stella hinted above, partners occupy a space of uncertainty, a third space of 'not knowing' between seropositivity and seronegativity. An HIV test will only confirm that they were HIV-negative some weeks before the test was taken, but not whether they are still HIV-negative in the present moment. Some negative partners experienced this as a loss of identity, or as a kind of non-identity. Maria explained that she stopped having regular tests because they did not really mean anything and she did not want to put herself through the stress. At one point she decided she needed to have a 'real' test:

I found eventually it got to the point where I had to say to [partner], 'I don't want to have sex for quite some time. I *need* to know if I'm negative. I've lost the plot. I want a test that is truly negative.' ... It was so funny, I was so kind of, 'I'm truly negative. I'm truly negative.' And I had another test [laughs] just for the pleasure of having a true test, a test that actually meant something.

The non-identity of an uncertain serostatus sometimes compelled even partners who were not sexually active to have regular HIV tests. Gavin's partner Katya, aged 50, said she knew it was not rational under the circumstances, but felt she needed to check every so often 'just to, you know, to be sure'. Most partners, however, did not test regularly, although all partners had had an HIV test at some point in the past. Some partners rationalised that regular testing was not necessary if appropriate precautions were in place, while others did not see it as important. There were no obvious parallels between testing and

unprotected sex, but the lack of regular testing by partners was sometimes a source of anxiety for positive partners. Participants were not asked about their knowledge or use of post-exposure prophylaxis (PEP), and only one couple mentioned having used PEP after an incident when a condom broke.

Having children

Reproduction in the context of HIV tends to be focused on women, both medically and in the available research literature (see Sherr & Barry, 2004, for a UK comparison). Today, having children is an option available to many positive women in Australia. According to Australian surveillance data, mother-to-child transmission of HIV is very low with the use of preventative interventions, including antiretroviral therapy, Caesarean delivery and avoidance of breast-feeding (McDonald et al., 2001; National Centre in HIV Epidemiology and Clinical Research, 2005). However, reproduction is much more complicated for positive men and negative female partners. Maternal infection is an issue. Reproductive technology such as sperm washing is not readily available and the current cost is prohibitive for many.

Initially, testing HIV-positive was a crushing blow to many participants' hopes of having children. 'I've always wanted to have a child, you know, and live with them,' Mahmoud said. 'That's what just shattered me; I thought that opportunity was gone.' Similarly, Zoe said: 'I thought all these stupid things, because I didn't know. I didn't know you could have kids.' However, at the time of interview, all the positive women and most of the positive men knew that having children was possible when positive, although understandings varied as to how. Zoe observed:

Yeah, I know that I can. It's just finding the right person and then, you know, when we're ready to go and talk to people about how we're going to do it, you know? Because I know you can't really do it the natural way, but I know that you can have children.

Two participants were trying or planning to have children with their respective partners and they approached the matter differently. In both couples, the male partner was negative. Olivia, aged 33, said that getting pregnant was 'tricky', because she and her husband always used protection. They had chosen to use condoms and a syringe, which was laborious and awkward. 'It sounds so clinical, it's icky, but we try and make it a little bit fun ... but doing that repeatedly gets really hard.' Simon and his positive partner Linda were planning to have children in the near future. He observed that there was a risk because 'it's got to be done the conventional way' and planned to take pre-exposure prophylaxis (PREP) as a precaution. 'It's

a risk you've got to take because the outcome is worth it.' They had not looked into any other method in detail.

It's all I've ever wanted, you know, to have a kid, and like have a family, you know ...

Audrey, aged 36, was diagnosed during pregnancy. Her child from this pregnancy was HIV-positive. Audrey subsequently had another child. She and Ellen were the only positive women in the study to have had children following diagnosis. Both pregnancies were unplanned and occurred through unprotected sex. Both children were HIV-negative. Ruby, aged 34, and Zoe, aged 24, both spoke of wanting to have children. They did not see HIV as a barrier per se to having children. The issue for them was finding the right partner. In this respect, HIV was seen as a complicating factor. Ellen faced the same issue prior to her pregnancy. At 36 she was in a troubled relationship and had resigned herself to not having children when she fell pregnant after a rare and unintended episode of unprotected sex with her then partner:

I'd always wanted children but had never been in a situation, I guess I'd never been in a stable relationship or long enough to kind of be in that situation. And when I was in that sort of 36-, 37-year period, I kind of resigned myself to the fact that, okay, I'm not going to have children. It wasn't something I was happy about but I just thought, okay, I'm just going to accept it; this is how it is. And then it just happened and I mean I was ecstatic!

Parenthood is significant to the formation and validation of heterosexual gender identity in most cultures. This was evident in many of the stories. When Jason, aged 23, first met Audrey, his brother found out about her HIV status at a local pub popular with members of their cultural community and confronted the new couple. His brother fiercely opposed Jason's relationship with a positive woman, causing considerable tension between the

two brothers for some time. Jason said that his brother's attitude changed only after Audrey had their baby:

Yeah, he's all right now. He's come to terms and he's respected Audrey and he's respected me, because now he's got a beautiful niece, yeah, and that's changed his whole view of Audrey and me. Yeah, he's come to respect her. I love that, I love it when he's respectful, when he shows respect to her.

Similarly, Mahmoud, aged 30, had long struggled to come to terms with himself as a man with HIV. Meeting his partner was a turning point. When interviewed, Mahmoud and his partner Amy were expecting a child together, another unplanned but welcome pregnancy, which occurred through unprotected sex. At the time of the interview Amy's serostatus was unknown and they were waiting for her test results. There was much at stake:

Well, I'm scared and I'm excited, because I'm just waiting for the next result. After the next result, if it's all good, I'll be over the moon, you know? It's all I've ever wanted, you know, to have a kid, and like have a family, you know, and live with them at home, because with my son, I only lived with him for a year and then I went to jail, you know, and he grew up while I was in jail. I missed out on that, and that hurts.

(Mahmoud)

Several men spoke of their desire to be fathers and their sense of loss and sadness over not having any children. HIV was seen as a major obstacle to fatherhood, not necessarily in a technical sense, as most were aware of sperm washing, but in terms of finding a partner who would be accepting of them as positive men. For them, this was the biggest and most emotional impact of HIV on their lives and their identities. 'I see every day married couples, their kids and that, and it just tears at my heart,' said Kevin, aged 57, who had been positive since his 30s. 'Talking about what HIV has done to me; that sort of really makes me think, "Wow! I can't have kids."' Some men hoped to 'find a girl with the same condition that wants to give it a shot,' as Evan, aged 43, put it, while others sponsored children overseas or stayed in touch with stepchildren from previous relationships.

5 Services and community

Services and support

The vast majority of participants typically had little or no contact with non-medical HIV services, organisations or with communal forms of positivity. However, everyone had accessed at least one service at some point. The most frequently mentioned services are documented below. Participants were not asked to name all the services they had ever used. Rather, the services mentioned came up during conversation and should therefore not be seen as exhaustive. As discussed in this chapter, there were several reasons for the participants not wanting to use services, as well as several barriers.

For their health and medical needs, most participants went to sexual health clinics and major hospitals, with only a few visiting inner-city doctors with high

convalescent/respite care. The Haven is open to all people affected by HIV and, according to the organisation, about 45% of its clients are heterosexuals. Most participants were aware of these two services and many had visited one or both at least once, but access tended to have been in the past or to have been sporadic rather than regular.

Most participants obtained their HIV-related information from their doctor, their HIV-positive partner and Pozhet via mail-outs. For many this was their primary contact with Pozhet and was seen as essential and supportive. Participants did not regularly attend peer support groups but, for those who did attend, Pozhet was the most commonly mentioned group. Some had attended support groups organised by sexual health clinics and hospitals. Only a few had attended such groups at the AIDS Council of NSW or at Myrtle Place, run by NorthAIDS, a government-funded community organisation providing services for people with HIV on Sydney's North Shore (this service has since closed).

[T]here were several reasons for the participants not wanting to use services, as well as several barriers.

case loads of HIV patients (health and medical issues will be explored in the second phase of data collection). Other than medical services, the most well used and highly praised service was the Bobby Goldsmith Foundation, which provides practical, emotional and financial support to people with HIV/AIDS and is financed by donations and corporate sponsorship. A quarter of participants received regular financial assistance from this service.

Among the most frequently mentioned services was the Heterosexual HIV/AIDS Service NSW, commonly known as Pozhet, Australia's largest peer education program for heterosexuals with HIV. Funded by NSW Health, Pozhet provides peer support, workshops, social activities, retreats, regional outreach and 1800 free-call counselling and information. Also frequently mentioned was the Western Suburbs Haven, a partly government-funded volunteer organisation and registered charity, which provides drop-in facilities, food service, social activities, information, advocacy, workshops and

The government-funded AIDS Council of NSW (ACON) was well known to most participants, but not frequently accessed. When participants did consult ACON, reasons included housing assistance, family assistance, referrals, information, treatment information and discount vitamins. Some had had counselling through ACON, but counselling was more commonly sought through the Albion Street Centre Psychological Unit (part of South East Sydney Area Health Service), which provides free and unlimited counselling, or through Ankali, a volunteer community service, which operates out of Albion Street and provides emotional and social support for people with HIV and their partners, families and friends. Several participants had also sought assistance from the HIV/AIDS Legal Centre Inc., a community legal centre that specialises in HIV-related legal matters.

Some families regularly attended the annual Camp Goodtime, a national camp for families with children affected by HIV, run by Sydney Children's Hospital and

funded by the AIDS Trust of Australia. Some families also visited Bear Cottage, a hospice for children with life-limiting illnesses operated by the Children's Hospital at Westmead and funded by donation. A few participants had made use of respite care at the Haven, at Des Kilkeary Lodge, run by NorthAIDS, as well as at the Bridge, an external facility of Royal Prince Alfred Hospital that provides residential care for people with AIDS dementia.

A handful of participants had visited drop-in centres for people with HIV, including the Positive Living Centre, which is managed by ACON and provides social activities, skills building, special events and complementary therapies, as well as NorthAIDS' Myrtle Place, which offers lunch, peer support, massage, computer access and courses. A few had also visited support services for people with HIV, including the Sanctuary, a community health service offering free natural therapies and social activities, and the Luncheon Club and Larder, a registered charity and volunteer organisation providing weekly lunches and food items. Participants used these services and centres primarily for specific things, such as massage, acupuncture, lunch, movies, food items and hair cuts. Again, contact was intermittent and only a couple of participants were regular visitors. Moreover, only men reported having made use of these places.

Contact with services was more common in the early period following diagnosis when people were looking for support and finding out what was available, or when they had experienced illness. Other than for financial and medical support, standard HIV services were not generally seen as ongoing or primary sources of support. However, as a result of the pressures of secrecy and the need to control information about their status, as well as the paucity of personal and professional support, many participants tended to form close connections with trusted *individual* staff within service providers such as the Haven, Pozhet, Bigge Park Centre and other sexual health clinics, and the Tree of Hope, a Centrecare facility that provides emotional support, pastoral care, home and hospital visits for people with HIV and their families.

Many participants drew considerable emotional and social support from these individuals, as well as from a range of other sources. Partners and family were central, as were close friends. Many nominated themselves as their main source of support, either out of necessity or a need for self-reliance and independence. Another significant theme was religion, with several participants stating that their faith, God, church or parish priest was a major source of support.

While many participants did not access HIV services, they often expressed a sense of reassurance that 'they are there' should they need them. There were a number

of reasons for participants not using HIV services more regularly. Not wanting to 'abuse the system' was a regular comment, including among those who were in genuine need of support. Their insistence that others were in greater need than they were could be read as an attempt to maintain a sense of normalcy or comparative good fortune in their own struggle. Not wanting to take up an identity as a person with HIV, or as a sick and 'needy' person, was an implicit theme in many explanations for participants' reluctance to access HIV services and support. A related theme was that of self-reliance and independence, of seizing control over their own destiny, which suggests that services were largely perceived through negative connotations of 'welfare'.

Inaccessibility and lack of transport were other major barriers to contact with HIV services, drop-in centres and support groups. Most participants lived in outer Sydney suburbs while most services were located in the inner city. The considerable cost of owning and driving a car was out of reach for many who received the disability support pension or worked part-time. Other reasons for not using services included work and family commitments, a lack of interest, and a sense of not quite 'fitting in'.

Cultural outsiders

There were significant cultural barriers to sustained contact with services and with communal forms of positivity. Many participants felt that major HIV services were alienating, or did not meet their needs or provide specific support for heterosexuals, or for serodiscordant heterosexual couples and families. Some parents argued that many services were inappropriate for children, either because they did not cater for children or because they were attended by clients with complex needs. Others spoke of visiting services where some clients appeared to be drug users, which made them feel uncomfortable, or edgy if they were in recovery themselves.

Those who had attended peer support groups run by major HIV services generally said they felt welcome and accepted, but nevertheless felt out of place because they were often the only woman or heterosexual man in the group and because the discussion tended to focus on gay men's issues. For the same reasons, many who had visited drop-in centres or services never went back. 'I feel uncomfortable going to just an HIV place or meeting, when it was just full of gays,' Gavin said. While an initial reading of this might suggest homophobia, numerous participants expressed concerns about being misunderstood in this respect. Rather, they emphasised a clash of identities, which made it difficult for many to walk in to ACON and other services perceived as explicitly gay-oriented, not because of discomfort with gay men,

but because of discomfort with stating their own sexuality in an unfamiliar environment, not knowing what kind of reaction they would get. While stating one's sexuality is not a requirement when accessing service provision for positive people, some participants felt it necessary in order

... the shortage of, not services but, an overview and perspective on straight HIV people is profound, I think ... they don't fit ... There's no place that they actually plug in to.

to access the right kind of support (such as peer or family support), or because they were unsure whether they were 'allowed' to use the services, or because they did not want their sexuality to be assumed.

HIV services in NSW are open to all people with HIV, regardless of gender and sexual identity. Yet, the particular language and imagery commonly used in the sector, along with the explicit focus of some services on gay, lesbian and transgender communities, contributed to a sense of exclusion among participants or to a perception that many HIV services were not for them. This perception, coupled with the association of HIV with homosexuality more broadly, constituted a considerable barrier to accessing services and support for many participants. Dean, aged 49, said:

It is difficult for me to have my condition defined in a foreign sexuality to me, and have the services almost shaped around that. And that's completely separate to—like because I think there should be gay everything, really, I've got no problem with that. But the shortage of, not services but, an overview and perspective on straight HIV people is profound, I think ... they don't fit. I think what I'm trying to say is they don't seem to fit. There's no place that they actually plug in to, whereas gay positive people seem to at least have a place to plug in to.

On the whole, there was a pervasive sense of being cultural outsiders in a positive gay community, but also of being largely invisible or marginalised in the HIV sector. The position of heterosexuals in the HIV sector is a complicated one. There are historical and cultural reasons for the sector being primarily focused on gay men. The majority of participants recognised that the gay community had been disproportionately affected by the virus and that it had been intimately entangled with the HIV epidemic from the very beginning. They often bore this in mind

when talking about services and many were explicitly grateful to the gay community for having lobbied and fought for treatments and services that might otherwise not have become available.

The participants readily acknowledged the history and achievements of the gay community in relation to HIV. At the same time, many struggled to perceive and articulate their own place in the HIV landscape. The perception of exclusion expressed by many participants is a dilemma grounded in the specific conditions of the epidemic in Australia and not necessarily based on explicit policies or actions. Nor is an excluding environment necessarily intentional or even conscious. Rather, because of the historical connection between HIV and gay men in Australia, a community and a sector has developed that has a culture, language and particular ways of relating that are safe and meaningful for that community, but not always perceived as safe, welcoming or supportive by those living heterosexually with HIV, including negative partners and families. In addition, as discussed below, building an alternative HIV-positive *heterosexual* community is complicated by a range of cultural, demographic and geographical factors.

Positive heterosexual community

Studies have shown that real or virtual connections to people in a similar situation help positive heterosexuals and couples to deal with stigma, alleviate isolation and feelings of marginalisation, and legitimise their experience (van der Straten 1998, pp. 543–545). Peer support was seen as essential by many participants. Yet, the vast majority did not feel they belonged to a positive community, nor did they articulate a sense of shared identity with other heterosexuals living with HIV. There were several reasons for this.

Firstly, few participants had close friends with HIV. Most had little or no contact with other positive people. The contact they had occurred primarily through Pozhet and the Western Suburbs Haven, but they rarely, if ever, socialised with each other outside of that context. For negative partners, contact with people in a similar situation was even more limited and occurred almost exclusively through Pozhet.

In NSW, Pozhet is the only service specifically for people living heterosexually with HIV. Most participants were aware of Pozhet and many had accessed one or more of its services and events at some time. Pozhet was generally seen as a very important service because it provided participants with the face-to-face contact with peers that they rarely experienced, and a sense of legitimacy and voice. Being around other people without having to

hide anything or lie about themselves was a liberating experience for many: 'You feel more free. You don't have to be watching what you're saying,' Grace said. They valued having access to a space where they could 'share experiences' with people in a similar situation and where they could 'be themselves', as Meagan put it: 'I feel comfortable, because I know there's a part of me then that I don't have to shut off.' Similarly, Kevin explained:

It's the only time, really, I'm in relationship with anyone ... I feel so relaxed and at home, you know? That's the only time I feel a person again really ... We're not talking about it, but I feel relaxed ... And nobody asks how you got it ... I feel good; I feel part of the human race again instead of feeling a freak, really.

While Pozhet was a highly valued service, it was generally seen as under-resourced and constrained in its capacity to facilitate everyday peer contact and community building. On the other hand, participants' ability to regularly attend Pozhet events was constrained by work demands, family commitments, geographical distance and transport difficulties. Other opportunities to spend time with positive heterosexuals were rare because of a lack of peer support groups in their local areas. In turn, intense secrecy among positive heterosexuals and resulting concerns about confidentiality were significant disincentives to initiating such a group. This lack of community was often contrasted with perceptions of a cohesive positive gay community, a perception not necessarily matching reality. Lucy, a partner, commented:

The heterosexuals with HIV just *don't* have that ability to meet. There is no community. I mean, Pozhet has sort of created a community, but it's still very disparate, it's very scattered and it *only* is a community when they meet ... there's no actual community as there is with the gay community where you can walk into the public and see people you know.

There were other reasons for not attending Pozhet. A few positive men who were single felt that Pozhet was mainly for couples. Some parents were reluctant to attend because Pozhet did not specifically cater for children. Some mistakenly thought that Pozhet was run by ACON or by 'gay people' and therefore 'not really for heterosexuals'. Others felt they did not fit in because Pozhet clients were perceived to be much older or younger than they were. There were those who did not want to spend time with other positive people because they did not want to be reminded of their own status, or because they did not want to be around 'sick' people, as Mahmoud explained: 'I don't want to know. I don't want to see it. Because it makes me – anything that makes me think about it, I don't want to know nothing about, you know?'

Lack of identification was a notable stumbling block to community-building. When talking about other positive heterosexuals, participants' accounts were often characterised by distancing and by an emphasis on differences rather than commonalities. Others were described as being 'strange', 'unusual', 'depressive', 'too negative' or 'too focused on their illness'. Such comments can be seen as narrative devices that instate the speaker's own 'normalcy', or their comparative health, positive attitude or coping strategies in the face of HIV. Distancing and lack of identification also hint at the diversity of those living heterosexually with HIV, which Olivia referred to as 'a real mismatch of people'. Differences in background, education, class, ethnicity and life experience were perceived by many participants as inhibiting the possibility of a shared positive heterosexual identity and community. This diversity was sometimes interpreted through personal politics and moral views, which acted as another barrier. Donna, for example, said:

I don't find a lot of compatibility at those support groups. I don't find other women with the same interests as me, their socio-economic, their lifestyle ... there's a lot of snobbery with the HIV. I don't know that I've got that much in common with men who put needles in their arm. I don't know that I have a lot in common with women who get it through promiscuity or through drug use. I don't have that much in common with them.

Some found these kinds of differences difficult to negotiate when attending Pozhet or the Haven, either because they felt they were being treated with disdain by others or because meeting people from a different background was a new experience that took them out of their comfort zone. For example, Claire, a partner, observed: 'Being around people who have an illness that's not generally accepted, it's still unusual for me because I don't mix with people like that ... I feel really awkward about it.' Gavin spoke of class distinctions among positive heterosexuals:

The ones that I've met, they seem to be only very professional-type people and they don't want to know about the common-man type thing. If you want to put class distinction in it, I find a lot of class distinction there. They say, 'Oh, what do you do for work?' 'Oh, I worked as a truck driver.' 'Oh, is that all you did?' ... [The Haven] was a wider class of people. They were good ... they seemed to be western-suburbs-type people and I can more identify with western-suburbs-type people because I've been in a working-class-type situation most of my life. So they were easier to get along with and I found them more open and more easy to joke about things.

As in Gavin's account, similar background and social position were more commonly described as points of connection and identification than was HIV status. However, many also described how differences were transcended momentarily when connecting around HIV, or when spending time together at events organised by services such as Pozhet. These events were seen as facilitating a unique sense of support, sharing and understanding that they did not experience in their everyday social relationships or environments:

Yes, you do connect ... if you go into those groups, you can feel the kindness and you can feel the understanding. And that is sharing. This is why people hang around and don't go home because they are just soaking it up ... You can transcend a lot of class and race issues as well, even though if you leave and go down the street you wouldn't have much to say to each other perhaps, in ordinary life. But *there* you can sit and talk about things.

(*Maria, HIV-negative partner*)

In this way, statements of identification with other positive people were often highly qualified. HIV was described as a 'tie', a 'meeting point', a temporary 'bond' between disparate people, rather than as a basis for a coherent community. Ellen commented:

To some degree there's a special bond there, maybe with certain people that I would probably not normally befriend because they are maybe a bit different to me, or whatever, but because there's that special secret that we share, it kind of gives it a different sort of connection.

In short, the building of a positive heterosexual community is complicated by a range of significant factors. Firstly, the number of positive heterosexuals in NSW is relatively small. Secondly, participants felt like 'cultural outsiders' in the HIV sector and in the community of people living with HIV/AIDS, which constrained their access to HIV services and support. Thirdly, there was a general disconnection from other positive people and communal forms of dialogue and support around HIV. Fourthly, there was a lack of readily available resources, services and support specifically for heterosexuals living with HIV, and existing services catering for this population were seen as under-resourced. Lastly, their own social and cultural diversity, along with their geographical dispersal, also made it difficult to constitute a community or a positive heterosexual identity.

In another sense, this lack of a positive heterosexuality also reflects the general invisibility of HIV in mainstream social environments and media, as well as the persistent absence of references to heterosexuality in much of the language, educational material and publications of the HIV sector. The general lack of mutual engagement between the HIV sector and the participants is problematic in that it may disenfranchise and increase the vulnerability of those living heterosexually with HIV by limiting their access to information, services and support. In light of this, the HIV sector needs to think carefully and creatively about how to reach and engage this population. This may require a broad sector approach, which would most productively entail building on existing strengths and sharing strategies identified as effective.

6 Positive futures

'Life is a bowl of cherries. But it is a compromised life because of HIV,' Donna said. As described in this report, HIV shaped the lives of participants in many and profound ways. At the same time, they showed remarkable resilience and resolve in their everyday living with HIV and in their ability to negotiate its many difficulties. Their stories were interspersed with a desire to stay active and healthy, to maintain a positive attitude and to 'get on with life'. And that they did, in many different ways, by focusing on their work and careers, their families and children, or by getting involved in their local community, in their church, in sports, in the arts. Some travelled a lot, and not an insignificant few dated, got married, or had babies.

The participants' outlook on the future can be summed up as cautious but optimistic. For some, this outlook translated into a 'realist' approach of carefully planning for every eventuality, should they or their partner get sick or die. Others preferred to 'live one day at a time', avoiding too much planning, and instead focusing on making the most of each day, as Rowan put it: 'I do see it in the sense that today's good and I've enjoyed my day. I live on a daily basis.'

Very few participants expressed fears of dying, but the theme of death was often implicit in their narratives of the future. Concerns about the effects and efficacy of treatments were common, particularly among positive men and negative female partners, which is understandable given the generally poor health of many men in the study. Positive women were more likely to express concerns about staying well for their children. They also worried about what would happen to their children should they become sick or die. A few participants believed they were experiencing the onset of dementia and worried about the ramifications of this, especially if they were alone or if they had dependent children. Despite these concerns, many did not believe they would die of AIDS. This belief was sometimes an expression of defiance or denial, but more commonly they pinned their hopes on advances in treatments and medical science. Hopes for a cure were extensive, as if they refused to accept that HIV was forever.

Nearly all said they wished they did not have HIV. However, many participants, including negative partners, felt that living with HIV had changed them for the better in some ways, that they had gained valuable insights from the experience. Those who had endured intense grief and suffering often found that it profoundly altered their awareness and understanding of life and of themselves. HIV was often described as 'humanising', with many saying they had become more tolerant and open-minded. A greater sense of acceptance and understanding of difference sometimes

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As they carved out spaces of meaning and purpose for themselves, many had a sense of future that would have been unthinkable only ten years ago. Those diagnosed prior to the introduction of combination therapies in 1996 were told they had only a few years to live. Like many diagnosed in the early epidemic, they sold their assets, borrowed money, went travelling and made no plans for the future. Since then, their timeframes have gradually lengthened. Yet they still perceived the future as relatively uncertain. The same was true for most participants, who tried to balance plans for the future—career, finances, pregnancy, travels—with the uncertainties of the virus and of treatments. The future appeared similarly uncertain for negative partners, whose lives and destinies were often meshed with those of their partners and shaped by the vicissitudes of their partners' illness.

translated into deeper feelings of humility and compassion for others. For many, learning to live with stigma and an ever-changing illness had fostered qualities such as adaptability, resilience, strength and independence. Others described how they had become more appreciative of life, how HIV had put their life into perspective in terms of what was important and what was not.

Because of secrecy, such insights and changed perspectives were rarely shared with the outside world. Largely disconnected from the broader sector and

positive community, many participants, families and couples had withdrawn into close, but isolated, micro-ghettos of support and silence. This provided protection from social stigma and prejudice, but also meant that their experiences of living with HIV were 'not accessible to others to effect change in the wider society' (Spirig, 2002, p. 1332). This report hopefully goes some way towards breaking this silence and making known the diverse and complex experiences of living heterosexually with HIV.

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