

Men and women living heterosexually with HIV: The Straightpoz study, Volume 2

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MONOGRAPH 1/2009

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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.

Executive summary

HIV and treatments

Uptake of antiretroviral treatments (ART) for HIV was high among the HIV-positive study participants. Largely disconnected from the HIV sector and from peers, and faced with the stigma and silence surrounding HIV in heterosexual society, participants were greatly invested in medicine as a key mechanism for managing and compartmentalising HIV in their lives. Treatments were imbued with a capacity to reverse or lessen the everyday impact of HIV and thereby provided a reassuring sense of normality or, at the least, an acceptable holding pattern. Children and partners were often a major motivating factor in the uptake of treatment, but they were rarely part of decision-making about treatment. Most positive participants saw treatment decisions as a matter for them and their doctor.

The findings do not support the emphasis in recent HIV literature on a supposed shift from a traditional doctor–patient model to a partnership model where treatment decisions are made jointly on the basis of combined expertise. Few participants subscribed to the neoliberal idea of the ‘expert patient’. Authority and expertise were firmly located in their HIV doctor, and most relied on their HIV doctor to keep up with the latest medical developments, to inform them when necessary and to act in their best interest. As was consistent with their strong faith in and reliance on medicine, the participants expressed a strong commitment to adhering to treatment and to continued treatment in the future. Two-thirds were expressly opposed to the idea of having a treatment break or tinkering with their treatment in any way. Sticking to successful treatment provided a certain sense of security and reassurance, whereas a treatment break was associated with the unknown.

Health

For positive participants, HIV was rarely their only health condition and many were taking medications in addition to ART. But many health conditions were directly or indirectly related to HIV or to treatments. Several participants also described mental health problems, as well as past or ongoing drug and alcohol problems, which often overshadowed HIV. Even so, most rated their current health status relatively highly. Personal assessments of health were not straightforwardly related to how many years they had been HIV-positive or to physical symptoms but rather were framed by social, cultural and biographical meanings. Most participants felt they had some power to influence their health despite HIV.

Negative partners tended to rate their health less favourably, even though they reported far fewer physical health problems. Depression and stress were quite common. About half said their well-being was affected by living with HIV because of stigma, secrecy, isolation and concerns about their partner’s health and the future. But many couples also emphasised mutual support around health and well-being. Because many couples did not disclose their situation to other people, they tended to be quite isolated and reliant on each other for support. Yet the impact of HIV on negative partners’ well-being was often a delicate issue not easily addressed in couples because of the burden of responsibility it might evoke in the positive partner. The findings clearly show that HIV can affect the health and well-being of both positive *and* negative partners. Yet this is rarely acknowledged in the HIV sector, nor are the experiences of negative partners as people who ‘live with HIV’ in their own right.

Health services

For their HIV health needs, nearly all participants attended HIV clinics in major hospitals or sexual health clinics in urban, suburban and regional areas. Only one attended an inner-city general practice with a high HIV case load. Three-quarters were attending the same HIV doctor or clinic where they were diagnosed or which they attended shortly after diagnosis. Due to its stigmatisation in heterosexual society, most participants had compartmentalised their HIV-positivity to the clinical relationship. Given that their HIV doctor or clinic was often their primary or only contact with the HIV sector, and given that it was often one of few contexts in which they had actually disclosed their HIV, they tended to place considerable importance on this relationship as a safe and segregated space where their HIV status was cared for and their humanity validated.

The strength and supportiveness of the participants' relationships with their HIV doctors is heartening. But it also makes them highly reliant on and therefore vulnerable to any changes in primary care. Also, outside of this clinical model, their interactions with non-HIV health workers tended to be more complicated. As hardly anyone saw an S100-prescribing GP for both HIV-specific and general health care, most needed to go to GPs for any non-HIV-related health issues. Establishing a satisfactory relationship with a GP was not seen as easy. Disclosure of HIV to GPs was a vexed issue for most, due to privacy concerns and due to a perception that there was widespread ignorance about HIV in the general health sector. Almost all had experienced judgmental or discriminatory treatment by a GP or other health workers. Many negative partners encountered similar treatment when seeking an HIV test or when disclosing their situation to a GP.

HIV and sex

Among serodiscordant couples, both partners were aware of HIV. Positive partners had disclosed their HIV status to their negative partners who were generally well-informed about the possibility and risk of HIV transmission. A desire to prevent transmission was the norm among study participants, irrespective of their HIV status. Nearly all participants interpreted safe sex to mean the use of condoms with any penetrative sex. But this textbook definition did

not always translate into practice. Half the serodiscordant couples practised unprotected sex. Among those who were not currently in a relationship but who had been sexually active since diagnosis, nearly all had had serodiscordant sex, with over half having had consensual unprotected sex with a negative partner to whom they had disclosed. However, these couples did not necessarily consider their sexual practice as unsafe, although some did, with most relying on mutually agreed alternative risk-reduction strategies, including withdrawal, putting a condom on before cumming, abstinence or condom use during menstruation or illness, no anal sex and an undetectable viral load. These strategies were seen as reasonable precautions against the risk of transmission in light of current knowledge. A partner's ongoing HIV-negativity reinforced the sense that the right balance had been found between safety and acceptable risk.

Unprotected sex among couples did not depend on the gender of the positive partner. Yet a range of complex emotions and heterosexual gender dynamics were at play in the couples' sexual practices, including a general lack of a safe-sex culture among heterosexuals and the idea that condoms were incompatible with romance and 'natural' sexual spontaneity. Also, intimacy with and acceptance by a negative partner provided 'protection' from feelings of difference and stigma and thus provided a reassuring sense of normality for positive partners. In some couples this removed any rationale for having protected sex. Unprotected sex was often framed by both partners as the negative partner's choice. Yet many positive partners were deeply ambivalent and described a tension between the pleasures of unprotected sex, concerns about transmission of HIV and the ambiguity within the relationship of ultimate responsibility for HIV transmission.

Most negative partners did not test regularly for HIV. There was no obvious parallel between testing and unprotected sex. In both phases of the study, regular and non-regular testing was fairly evenly distributed among couples who had unprotected and protected sex or no sex at all. This is indicative of the complex factors at play in partner testing. Some partners saw the test as meaningless because it could not confirm an HIV-negative status in real time. Others saw it as unnecessary if appropriate precautions were in place, while some did not see it as a priority or did not want to know their HIV status. Persistently negative tests were another reason for reduced testing. Other factors at play included a desire to not treat their positive partner as infectious and a lack of suitable health services for negative partners.

Introduction

Background

An estimated one in five people with HIV in Australia identify as heterosexual, yet they remain largely invisible in mainstream society, as well as in the local epidemic, and little is known about their experiences of living with HIV. While HIV is considered a heterosexual epidemic in many countries, transmission of HIV in Australia has predominantly occurred through sexual contact between men. Thus the history of the local HIV epidemic 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 two decades (Kippax & Race, 2003). Meanwhile, HIV has receded from mainstream awareness and today exists on the periphery of heterosexual society.

However, surveillance data show that in the case of 21% of new HIV diagnoses between 2003 and 2007, transmission

on the experiences of living heterosexually with HIV, not only in Australia but also 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, more rarely, heterosexual men.

There is an 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 of positive women: see Squire, 2003; Lawless et al., 1996; Crawford et al., 1997). While there are shared issues across affected populations, heterosexuals' experiences of living with HIV are culturally different from gay men's experiences because 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 heterosexuals negotiate living with HIV in this context? How does it shape their identity as social and sexual participants in heterosexual society? What are the implications for heterosexuals with and without HIV in terms of health, quality of life, sexual practice, relationships and sociality, or indeed prevention and health promotion?

The Straightpoz study was initiated in response to this gap in the research (a more detailed background to the study is provided in Volume 1, Persson et al., 2006). It is a qualitative longitudinal cohort study of positive heterosexuals and their negative partners in New South Wales, the first study of its kind in Australia. The study received ethics

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

was attributed to heterosexual contact. This represented a small increase in such diagnoses compared with the period 1998 to 2002 (National Centre in HIV Epidemiology and Clinical Research, 2008). In addition, lacking a culture of regular HIV testing that enables early diagnosis, heterosexuals constitute a substantial proportion of late presenters with an AIDS diagnosis (National Centre in HIV Epidemiology and Clinical Research, 2008; NSW Department of Health, 2006; McDonald et al., 2003).

In the HIV literature, heterosexuality is discussed almost entirely in relation to reproductive issues, risk behaviour and transmission. While there is a large body of research into the experiences of living with HIV, there is very little specifically

approval from the Human Research Ethics Committee at the University of New South Wales in 2004. It is conducted by the National Centre in HIV Social Research (NCHSR) in collaboration with the Heterosexual HIV/AIDS Service (Pozhet), the only service in New South Wales specifically for people living heterosexually with HIV. HIV-positive heterosexuals have long been a hard group to reach for social research. The reason this study has been successful has been its explicit focus on heterosexuality. The close collaboration between NCHSR and Pozhet through each stage of the research has been another important reason for the study's success.

The first phase of the Straightpoz study (2004–2006) explored a range of issues, including: key events around diagnosis; perceptions and knowledge of HIV prior to diagnosis; impact of HIV on identity and everyday life; stigma, disclosure and discrimination; relationships and sex; reproduction and children; social connectedness

This report explores findings from the second phase of the study, which focused on health and treatments, health services and sexual practice. 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.

and access to services and the positive community. The findings showed that HIV placed the study participants in a highly stigmatised position in heterosexual society, which shaped relationships and sexuality in often profound ways. The participants had developed 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 felt like 'cultural outsiders' in the HIV sector and were generally disconnected from other positive people and from communal forms of dialogue and support around HIV (Persson et al., 2006; Persson & Richards, 2008a).

This report should ideally be read against the background of the first report. This report explores findings from the second phase of the study, which focused on health and treatments, health services and sexual practice. 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 heterosexual experiences of HIV, and that the issues highlighted here will provide a basis for further research and for the continued development of appropriate service provision for heterosexuals with HIV and their partners.

Method

For the second phase of the study, participants were recruited from the existing cohort and via Pozhet mail-outs. In-depth, semi-structured interviews were conducted between September 2006 and May 2007, including 34 face-to-face interviews and one phone interview. Interview schedules for positive participants and for negative partners were developed in consultation with Pozhet and with the Straightpoz research advisory group to ensure that language, themes and questions were appropriate to the target group. Twenty participants asked to be interviewed at home due to confidentiality concerns, transport difficulties and convenience. Fourteen interviews were conducted in a variety of locations, including NCHSR, Pozhet, ACON (AIDS Council of NSW), the Western Suburbs Haven (a support centre for people with HIV), a sexual health clinic and a suburban café. The duration of interviews ranged from 30 minutes to three hours; the average length of an interview was two hours.

Interviews were conducted in a conversational style and explored the following themes: treatment histories, decisions and experiences; current health status and health management strategies; interactions with HIV health services and the general health sector; understandings of safe sex, sexual practices and negotiations; and HIV testing. 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 analysed to identify similarities and differences across the interviews, both among and between the three main groupings: positive men, positive women and negative partners.

A third and final phase of data collection is planned for 2009. The focus of this phase of the study 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, testing and pregnancy; and explore additional themes not covered in the first two phases.

Participants

To date, 47 people have participated in the Straightpoz study. In the first phase (2004–2006), 31 participants were interviewed, including 14 positive men, nine positive women and eight negative partners. In the second phase (2006–2008), 35 participants were interviewed, including 16 positive men, 10 positive women, seven negative female partners and two negative male partners. All the original participants were invited to participate in the second phase and 19 of them agreed. Two declined, three were ill or in hospital and seven were out of contact. Sixteen new participants were recruited. As in the first phase, recruitment of additional HIV-negative male partners proved unsuccessful despite several attempts.

Participants in the second phase of the study ranged in age from 23 to 71 years. Most positive men were in their 40s and 50s, while most positive women were in their 30s and 40s. Negative partners were mostly in their 20s or 40s. The second phase included more people in their 20s and 30s than did the first phase. Participants lived across and beyond Sydney, with a concentration in the inner and outer western suburbs. Two participants lived on the Central Coast and two lived in regional New South Wales. Another two participants lived in the Northern Territory and Queensland, but were included because of their previous participation in the study.

Among positive participants, eight men and four women were currently single. Six men and five women were married or in committed relationships. Another two men were in committed online relationships with positive women overseas, and one woman was in a new, tentative relationship. Five men and four women had divorced or separated since diagnosis and three men and one woman had been widowed by AIDS.

In the second phase, 19 participants were in serodiscordant relationships¹, representing 13 couples in all. In the case of six of these couples, both partners were interviewed and, among the remaining seven couples, only one partner was interviewed. One couple had separated but was included because the relationship had been long-term and sexually active and therefore provided important information about serodiscordance. In eight couples the man was positive and in five couples the woman was positive. Of the 47 people who have participated in the study to date, 27 were in serodiscordant relationships, representing 19 couples in all with either one or both partners having been interviewed.

In the case of 11 couples the man was positive and in the case of eight couples the woman was positive.

Participants in the second phase were from diverse cultural and linguistic backgrounds, including Anglo-Australia (the majority), the UK and Ireland, the Middle East, Melanesia, sub-Saharan Africa, North Africa, the Mediterranean, Eastern Europe, Northern Europe and South Asia. Two were indigenous Australians. They came from a wide range of socioeconomic backgrounds and life experiences and included, among others, retirees, business owners, factory workers, army personnel, single parents, former prison inmates, students, born-again Christians and public servants.

Twenty participants (five positive women, ten positive men and five negative partners) had children. Between them they had had 36 children, ranging from newborn to adult. Five children had been born following their parent's diagnosis. Two of these children had been diagnosed HIV-positive and one had subsequently died. Both of these children had been born prior to the introduction of combination therapy, and the mother of one positive child had been unaware of her HIV status before she became pregnant.² Two children were the offspring of serodiscordant couples, while one positive woman had conceived her second child with donor sperm following diagnosis. Two positive women were currently trying to conceive. Three children of current couples had been 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, seven were in full-time paid employment, one ran his own business, eleven received the disability support pension (three of whom did some casual or part-time work), three received the old-age pension, one man was studying and one woman was on maternity leave. Two men were illegally in Australia and could not return to their countries of birth because of the lack of health care for positive people. They survived with the help of charities, church groups and some casual work. Five of the 10 women worked, mainly full-time, while seven of the 16 men worked, three in a full-time capacity. Six of the nine negative partners were in full-time paid employment and two received the carer's allowance. Four positive men and one negative woman had spent time in jail; three of these men had served time more than once.

1 HIV serodiscordance describes a relationship in which one partner is HIV-positive and the other is HIV-negative.

2 According to Australian surveillance data, mother-to-child transmission of HIV is now very uncommon with the use of preventative interventions, including antiretroviral therapy, Caesarean delivery and no breast-feeding (A. McDonald et al., 2001; National Centre in HIV Epidemiology and Clinical Research, 2008).

Time since diagnosis ranged from 10 months to 22 years. Eight participants had been diagnosed in the 1980s, thirteen in the 1990s and five in the present decade. As in the first phase of the study, several participants had been late presenters. Seven of the 16 men had had a late diagnosis, four with an AIDS-defining illness. As a result, the health of some men in the study was poor.

Unprotected heterosexual sex was the most commonly mentioned mode of infection (in the case of 11), followed by needle sharing (3), homosexual sex (2) and blood transfusion (1). Two men and five women had been infected by their spouse or partner; two of these women's partners were from countries with a high prevalence of HIV. Eight participants were unsure how they had become infected. Of these, one man and one woman said they had been infected either through a medical procedure or through heterosexual sex, another man either through sharing needles or heterosexual sex, and yet another man thought he had been infected either through sharing needles or through sex with 'a drag queen'. Four men said they had no idea how they had become infected and one man did not volunteer any information.

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, the emphasis of this study is on how people *live* heterosexually with HIV. The phrase 'living heterosexually with HIV' emphasises heterosexuality as a social practice, rather than as an identity. It recognises the fluidity of sexuality and allows for diverse sexual histories, while drawing attention to the current sexual and cultural contexts in which people live.

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 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 HIV and treatments

The first phase of the Straightpoz study found that the participants perceived HIV to be highly stigmatised in heterosexual society and therefore kept the fact that they were living with HIV strictly secret. Various cultural, demographic and geographical barriers also meant that they had little contact with the HIV sector and with other heterosexuals living with

[P]articipants were generally greatly invested in medicine as a key mechanism for managing and compartmentalising HIV in their lives.

HIV. Largely disengaged from the positive community, they had developed 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. One such strategy was taking treatments. The second phase of the study found that participants were generally greatly invested in medicine as a key mechanism for managing and compartmentalising HIV in their lives.

The majority of positive participants to date (28 out of 34) were currently using antiretroviral therapy (ART). Almost all had been on treatment for HIV at some point since their diagnosis. Only three had never used ART. In the second phase of the study, which is the primary focus of this discussion, 21 out of 26 positive participants were on treatment. This level of treatment uptake contrasts with earlier Australian research, which found that heterosexual men and, in particular, women were less likely than gay/bisexual men to use ART (de Visser et al., 1999; McDonald et al., 2000b). But more recent research suggests that this pattern has changed and that rates of use of ART are now similar among heterosexual men, women and gay/bisexual men (Grierson & Misson, 2002; McDonald et al., 2005). The findings of our study reflect this shift.

Decisions and meanings

Decisions about treatment uptake were significantly shaped by historical and cultural context, including advances in the treatment of HIV, as well as the overrepresentation of heterosexuals among late presenters. A few participants had been diagnosed before any treatment was available. They tended to have long and complex medical histories marked by shifting uncertainty and hope, experimental doses of AZT (the first drug for treating HIV) and participation in clinical trials for new drugs. More than a third of the participants had started treatment immediately or soon after diagnosis, primarily due to illness or as a result of their doctor's advice. This was particularly common among those who had been diagnosed late with an AIDS-defining illness or with an impaired immune system, and to a lesser extent among those diagnosed during the 'hit early, hit hard' era (Ho, 1995).

Less than a third of participants had delayed treatment for some years after their diagnosis. Another five were not currently on treatment, although two had been so in the past. The most common reasons for having delayed treatment included an absence of symptoms of illness and not having been advised by their doctor to start ART. Less common reasons included a desire to maximise the benefits of future medical developments, scepticism or concern about the early HIV drugs, not having been referred to an S100 prescriber by their diagnosing GP, an unwillingness to face the fact that they were HIV-positive, and having had a lifestyle not perceived as sufficiently stable to manage a treatment regime.³

³ These and other reasons for postponing or not starting HIV treatment are documented by Gold & Ridge, 2001; Kremer et al., 2004; Pound et al., 2005; Randall & Barroso, 2002; Cooper et al., 2002; and Davis et al., 2006.

The significance of change

Regardless of when or if the participants had started treatment, one theme seemed to flow through most narratives on treatment decisions: the significance of change. The decision to delay or start treatment was often framed by a desire to either preserve or re-establish a sense of normality. This normality was both subjective and relative among the participants, but it was characterised by an absence of any noticeable or unmanageable changes to body and health and, by extension, by the ability to compartmentalise HIV and get on with life.

For those who had been diagnosed late with an AIDS-defining illness, starting treatment was seen as a necessary decision to try to reverse or minimise the physical impact of HIV. Among those who had delayed treatment after diagnosis, any sign that HIV had brought about some change, either in the form of symptoms of illness or an unwelcome trend in clinical markers, was often the catalyst that prompted the decision to take up treatment and restore normality:

I didn't actually have to. Like I wasn't being told by the doctors to go on it, but I could see a trend in my numbers that I wasn't comfortable with. So I just went, 'Nah. I prefer to go on [treatment] while I'm ahead, rather than try to recover that ground.' So that's essentially why I made that decision.

(*Olivia, 33, diagnosed 1989*)

Even among those who had been asymptomatic when diagnosed, change was at the core of their decision about treatment. As described in the Straightpoz report, Volume 1, the HIV diagnosis itself often caused a profound rupture to everyday life, regardless of any physical symptoms. A need to somehow counter this rupture compelled some participants to take up treatments without much delay. Often unfamiliar with communal discourses on living with HIV, they tended to entrust themselves to medicine and to the expertise of HIV doctors as a way to contain not only the virus but also their sense of terror at having found out that they had HIV:

Whatever the doctor told me, I did. You know, like, I followed all his directions ... I didn't know nothing about HIV. I was new to this. I never heard of anyone that had HIV. So I was just so scared and I just listened to what the doctor told me. I knew, like, he is a professional, so.

(*Mahmoud, 32, diagnosed 1999*)

For others who had been asymptomatic when diagnosed, but who did not start treatment, the absence of daily medication confirmed the absence of change. This might explain why some were slightly resistant to talking about treatments in the interview, as if even broaching

the subject positioned them as something other than healthy. The fact that their doctor had not advised them to consider treatment was seen as testimony to prevailing health and normality:

Well, the doctors haven't said to me that, you know, I need to go on any medicine. And, because I'm still healthy; like *there's no change* or anything. So, they don't give me any reason for me to be on medication yet ... Me, I just put it to the side and try to forget about it.

(*Zoe, 26, diagnosed 1998*)

However, all five participants who were not on treatment anticipated that they would start in the future. While the factors that would influence their decision to start treatment were different, these all pivoted on some notion of change. For Ellen, aged 45, and Angus, aged 53, the decision to start would be guided by subjective feelings of declining health. Ruby, 36, would start when advised by her doctor that it was time. Victor, 34, had settled on a CD4 count of 250 as his benchmark for starting treatment:

'I sort of got it locked inside my head that 250 is a sort of zone that I want to look at. I believe that I can hold out until then.'

The meanings of ART

Revolving around this theme of change, treatments held different meanings for different participants. For those who were on ART, undertaking treatment tended to be invested with a capacity to reverse or lessen the everyday impact of HIV and provided a reassuring sense

'If I have to take meds to keep it under control, well that's what I'll do. Because I'm not going to have this take over my life. I still do pretty much everything I've done for the last seven years. Nothing really has, has changed ... I want to get out there and live my life and, and all of that ... if I have to take 50 pills a day I will do that.'

of normalcy or, at the least, an acceptable holding pattern. They emphasised how treatments made it possible to engage in the same things as any other person, such as working and having a family. For Meagan, 47, treatments meant that: 'I'm well enough to work. So while I can earn money I can still live the life I want to live, within limits.' There was a sense that by keeping the virus suppressed,

treatments enabled them to disengage from HIV and continue to live, as far as possible, the way they had before diagnosis. Lydia, aged 44, said:

If I have to take meds to keep it under control, well that's what I'll do. Because I'm not going to have this take over my life. I still do pretty much everything I've done for the last seven years. Nothing really has, has changed ... I want to get out there and live my life and, and all of that ... if I have to take 50 pills a day I will do that.

Part of this theme of treatments and normalcy was the importance of staying on the right side of what many saw as the all-important line between HIV and AIDS. As long as that line was not crossed, some degree of normalcy was possible. To Ratu, aged 43, treatments were 'very helpful' because they were 'cutting off that bridge from HIV to AIDS ... So now you sort of live a normal life, except you're just popping pills'.

In contrast, for some who were not on ART, treatment loomed in the future as a marker of the end of normality, where the 'reality' of HIV would hit home. Ellen, 45, reflected: 'Well, it's quite daunting, obviously. And, and scary, and sort of, that sort of admission that there's something wrong with me.' Victor, 34, elaborated:

It is a big psychological thing for me that first day when I start treatment ... I believe there's three stages with HIV. You've got Stage One, which is where I'm at ... I have the virus but I don't need any medication. Stage Two is when you start medication. And although [the doctors] pretty much guarantee me that'll keep me out of the AIDS category for many years to come, yeah I think the darker stage would be Stage Three; if you get an opportunistic infection and find that you have AIDS ... And for me, to not progress from Stage One is a *huge* psychological barrier.

Thus, treatment was paradoxical in that it had the power to both signal and neutralise change, to both undo and restore normality. This capacity of treatment to carry multiple meanings was further shaped by personal biographies. In a Sydney study, Wong and Ussher (2008) identified three key meanings ascribed to treatments among their positive participants. These included treatments as *life savers*, as a *necessary evil*, and as a *last resort*. The first two meanings were readily observed in the Straightpoz interviews. The idea that treatments saved lives was a reality for several participants who themselves, or whose partners, had been gravely ill when combination therapy arrived in the mid-90s. Kevin, 58, who was in a hospice for people with AIDS at the time, said: 'We were all supposed to be dying, you know. But the combination came in and saved us.' Maria, 55, described how her partner narrowly escaped death because of treatments:

Treatments for me was like this sort of cliché of the cavalry rushing over the hill and sweeping him off to this new safe place that I had not prepared for at all. So I was totally put out by treatments because I was fully prepared for widowhood. And so treatment was unlike any previous drug option that we had. I think they're fabulous. How they're fabulous? Well, he's here because of them. They're, they're the drugs that I thought would not come in time ... [T]he understanding that he was alive, he was gonna live, was just so awesome. Awesome that he was gonna live. Fabulous! Oh, mm [becomes emotional] ... So treatments was monumental. Monumental! The biggest thing that's ever happened to me in my life was treatments.

The view of treatments as 'life savers' was not, as might be expected, unique to those who were diagnosed before treatments were introduced. Given that heterosexuals constitute a substantial proportion of late presenters with an AIDS diagnosis, it was a theme also found among those who had encountered HIV more recently. Phoebe, aged 36, whose husband remained critically ill following his diagnosis 18 months ago, said of treatment: 'Well, if he didn't take it he'd die.' This view was also articulated by two participants who were not on treatment, including Victor, 34, who, like many heterosexuals, knew little about HIV before his diagnosis in 2003 and thought of it as a 'death sentence'. In describing treatments, he mixed the themes of 'life savers' and 'normality':

I'd found out pretty much straight away; the doctor told me that antiviral treatment or HAART⁴, as they call it, was available in 1997 ... And once I'd found that out it was almost like a sigh of relief, really. I'd realised that, hey, I may need to pop pills some day on a daily basis. But wow, you know. They tell me that these drugs have brought people off their death bed, literally. I've heard that on many occasions, where people have been dwindling very close to death with AIDS-related illnesses. And once they got on the antivirals they just skyrocketed and basically got back to a normal lifestyle.

'Necessary evil' was also a common meaning attributed to treatments, although it was usually expressed in less laden terms as an 'unfortunate necessity', as negative partner Stella, 44, put it. Gavin, 48, said: 'I'm glad I'm on them in a way. But in another way I'd rather not be on them and I'd rather not have HIV in the first place ... I'd rather not be taking them but they're keeping me alive and they keep me feeling reasonably healthy.' In Wong and Ussher's analysis of this meaning, the benefits of treatments are 'tempered with undesired costs in the form of side effects' that diminish the quality of people's lives (2008, p. 463). This

4 HAART = highly active antiretroviral therapy

was certainly true for many participants who had to weigh the pros and cons of the effects of treatment (see later in this chapter). In addition, for Brendan, aged 48, chemical dependency was a major issue and was incompatible with a masculine discourse of self-reliance:

I fucking hate them ... But they're a necessity ... I'm relying on artificial shit to survive. You know? I'm relying on something to get me there. And it's like using a drug to fucking get through life. It's all bullshit ... It means I feel obligated to the pills, and I don't like that. I don't like being obligated to anybody for anything ... I mean I know you've gotta take them to knock the virus off, but I don't know.

The third meaning – treatments as a 'last resort' – was far less common and only articulated strongly by Angus, 53. He had steadfastly refused treatment since his diagnosis in 1992 because he remembered the 'days of the old AZT' and the adverse effects it had had on his late wife and friends. Having ignored the advice of his doctor for many years, he was only now starting to reconsider treatment due to his increasingly impaired health, but more so at the urgings of his young HIV-positive son who had been on ART since birth:

My health I think has failed me. But if it's HIV, old age, [drug] abuse, or the hep C, I don't know. But it is. And my son's been saying, 'Dad, get off your arse. Get on the treatments. Change your attitude ... I don't want you to die yet' ... He's the only influence that will get me to take medicine ... But yeah, it's still a lot that we've gotta overcome about it all.

Treatments and loved ones

As the above quote indicates, the emphasis on normality or necessity in the participants' decisions to start treatments was often coupled with other concerns. Wanting to stay well and alive for loved ones was a major motivating factor. Having recently married, Olivia, 33, said that she now

"The world had changed ... And all of a sudden I had to try and put it all together.

The only way to do that was to get on medication, get off the drugs ... I had to sort of look at it and say, "Well it's not me anymore. It's the kids." "

had 'a real huge incentive to stay well'. Staying alive for their children became a particularly burning concern for

those who had been widowed by AIDS, as was the case with several participants. Like Angus, Brendan, aged 48, had refused treatment for the first eight years following his diagnosis in 1992 because of his antipathy towards early AZT. But when he unexpectedly became a single father to two small children six years ago, he said that going on treatment became a means to pull away from a world of drugs and crime. The focus and regime required by treatments enabled him to get his life in order for his children:

I'd seen the victims of early medications mate, that fucking AZT. And they broke out in boils, they were sick as. I said, 'Why fucking take this shit? ... Life is not that fucking great to me that I'd have to go to that extent to keep it ... I'm not gonna be a guinea pig and I'm not taking your fucking pills.' Then I broke up with my girl and seven months later she was dead. And I had two kids. They were seven and ten. I thought, 'Fuck.' The world had changed ... And all of a sudden I had to try and put it all together. The only way to do that was to get on medication, get off the drugs ... I had to sort of look at it and say, 'Well it's not me anymore. It's the kids.'

Although children and partners were often a motivating factor in treatment uptake, they were rarely part of any decision-making about treatment. The participants would often discuss treatment options with loved ones, but the actual decision was seen as strictly personal, not as a joint decision. Brendan, who still lived with his youngest daughter, said: 'No, that's my decision, my life ... As for what I will and won't do, I answer to nobody but me ... I may explain things to [her], but in the final run, it's me and me alone. You know? I'm the one it affects.' Negative partners were often intimately involved in and affected by the everyday living with HIV. Yet, when it came to decisions about treatment, most positive partners drew a distinct line in the sand in terms of shared experience and impact. Corey, aged 48, explained why he felt his partner did not have a part in the decision-making:

My life is my decision. So I don't believe that anyone else can make that decision. You can talk to someone about it and maybe seek their opinion, their counsel. I don't have a problem with that. But I don't think that anyone can tell anyone else that they've gotta take a drug ... If it was a joint thing that we both had to take this tablet, that would be something that you would have to make a joint decision over. But if it's only affecting me ...

Most negative partners similarly framed decisions about treatment as the exclusive domain of their positive partner. Gabriel, 44, said: 'Ultimately it's her choice. It's her body. It's her life ... Even though it's gonna affect me ... *still*, it's her choice. And I won't try to interfere in that.' Maria,

55, explained that she did not get involved in her partner's medical decisions, because '[T]hat's his space ... I don't want to get in his way and I know he's doing it really well'. However, Alice, 23, voiced a common sentiment among the negative partners when she said that she was happy to leave the decision-making to her partner, providing the decisions he made were sound:

He decides what's best, and his doctor as well ... I'm glad that he discusses these things with me. But I'm happy for him to make the decision. Because it's his body and he probably has more idea than I would ... As long as he looks after himself then I'm happy for him to make whatever decision he likes. As long as it's a good one.

In other words, most negative partners kept out of treatment decisions as long as everything was working well and they felt confident that their partners knew what they were doing. As Maria, 55, said: '[H]e's very good at doing his best with his medication ... So I'm as safe as I can be.' She continued: '[But] if the [good] blood [results] suddenly stopped ... *then* I'd hop in and become the nurse. I would engage differently with the whole thing.' Claire, 40, said:

If things started to go a bit pear-shaped and [the treatments] weren't working anymore, yes, I'd like to be involved in finding out why and what can be done about it.

On the whole, most positive participants saw treatment decisions as a matter for them and their doctor. One reason for this was their generally strong faith in medicine and their particular respect for HIV doctors. But, as discussed below, the doctor–patient relationship was rarely perceived as a partnership in which treatment decisions were made jointly on the basis of combined expertise.

Information and expertise

Most participants were exposed to treatment information on a regular basis by virtue of being patients or Pozhet clients. The most commonly mentioned sources of information were, by far, the participant's HIV doctor and the community publications *Talkabout* and *Positive Living*, which many received via Pozhet mail-outs. Other sources included the internet (with women being the primary users), clinical nurses, social workers and, less commonly, treatment officers, health promotion material, pharmaceutical information leaflets and the mainstream media.

Research has found that access to information is an important factor in facilitating participation by patients in decision-making about treatment and in supporting their interactions with health care providers (Marelich et al., 2002). It is argued that the western HIV epidemic has brought about a democratisation of expertise in the

doctor–patient relationship. The traditional model of doctors as holders of knowledge has been progressively displaced by an 'expert patient' approach in which the patient is not only acknowledged as the 'authority on living with HIV', but in some cases has built up extensive and up-to-date knowledge on HIV and treatments rivalling that of their doctor (see Davis et al., 2006; Rosengarten et al., 2004; Brashers et al., 2000).

It is generally agreed that HIV advocacy movements have contributed decisively to this shift from a paternalistic model to a partnership model defined by a repositioned locus of authority and a two-way exchange of information (Epstein, 2000; Brashers et al., 2000). Due to the urgency and uncertainty of HIV, the early epidemic was marked by strong patient activism and a dynamic relationship between affected communities and health professionals, both of which became integral in shaping the clinical management of HIV (Ariss, 1997; Hurley, 2001).

Some HIV researchers have questioned to what extent this shift in expertise is real in practice (Moore et al., 2001; Stevenson et al., 2004). Others suggest that the partnership model may be specific to white middle-class gay men and their doctors (de Moor, 2005). It has also been argued that the 'expert patient' approach coincides with broader public health discourses in contemporary western society. Under the political conditions of neoliberalism, responsibility for health is increasingly located in the supposedly autonomous, self-governing individual. In this discourse, the ideal HIV patient has become constituted as an active and rational health consumer who is extremely well informed and assertive with doctors, attentive to test results and adherent to medication (Mykhalovskiy & McCoy, 2002).

The partnership model was largely absent in the participants' interviews, as was the idea of themselves as 'expert patients'. Most described a more traditional doctor–patient relationship in which HIV expertise was firmly located in their primary health care provider (however, their relationship with their doctor also differed from a traditional model in important ways, as discussed in Chapter 3). Only a quarter thought it was important to keep up with the latest medical developments in HIV, but only half of those considered themselves well informed and actively sought out medical information. 'I like to know what's going on, yeah,' Antonio, 71, said. 'I don't like to be just a guinea pig.'

Medical information tended to be more important to the participants when they were first diagnosed, but this typically lessened with time. Most would seek information only if there was a change in their drug regime. Some found the information too vast and complex, while some said they wanted to curb the prominence of HIV and move

on with their lives: 'I have enough HIV in my life as it is ... I tried to tangle with all that stuff initially ... it was like watching a race I wasn't interested in ... I'm not a doctor' (Dean, aged 49). Others grappled with conflicting emotions, feeling they *should* stay informed, while also finding it demoralising:

I read as much as I can but, oh, it depresses me a lot. And I have to read *Talkabout* when they send [it to] me, and *Positive Living*, every month. I've gotta read it to know what's going on, but it's just depressing and it just reminds me. It all comes back, the early days. Because now I'm sort of just living steady and don't want to think about it. Yeah, it reminds me of what I've been through with it ... just how it, it's ruined my life.

(Kevin, aged 58, diagnosed 1986)

However, many participants explicitly rejected a neoliberal discourse of the active, informed patient. As Tobias, 53, explained: 'I don't feel I need to read the paper every day and look for HIV treatments ... I really can't see the point. I'm probably getting the best medical care. Why buy a dog and bark yourself?' Like Tobias, most participants relied on their HIV doctors to keep up with the latest medical developments, to inform them when necessary, and to act in their best interest:

She's the expert. You know, so I have trust in her that she's giving me the right combinations. And I kind of don't really look into what it is [the drugs] do, because I don't really need to know. I don't want to know what the hell all these cells are doing in my body. As long as I'm healthy ... I just know that the drugs stop the virus from mutating. They kind of keep it at bay. That's about as much as I know about it. You know, as long as it does what it's got to do, yeah, I'll stick with what [my doctor] says.

(Lydia, aged 44)

The participants overwhelmingly viewed their doctor as the authority on HIV and treatments. In addition, many expressed considerable respect for and trust in their doctor. This comment by Carlos, 37, was typical: 'I really trust my doctor. She knows what's best for me. She's shown over time, I've experienced that with her. I trust her 110%.' Some had resisted treatment in the past due to concerns or scepticism, and several participants had insisted on changes in treatment due to side effects. But few questioned their doctor's expertise or advice in relation to changes in treatment:

He's the one who is more informed about the situation than I am ... I know if that happens he'll probably explain it to me properly, you know. 'This is what we've been researching, blah, blah' ... I'm sure he'd explain that to me and then I'd say, 'Mate, let's go for it' ...

Whatever he says goes. You know what I'm saying? Because he's the guy with the knowledge and stuff like that, yeah.

(Ratu, aged 43)

It is easy to see why participants invested so much authority and trust in their doctor, given their strong reliance on medicine as a strategy for managing HIV in their lives. But for this very reason, trust is partly an ideal, former Pozhet coordinator David Barton suggests. He notes that positive heterosexuals tend to be more critical of their doctor when they are with other positive men and women in peer settings. The participants' seeming lack of engagement with treatment information also needs to be seen in context. Positive heterosexuals typically have little contact with the HIV sector or with community activism. But in the right peer setting, treatment is often the main topic of conversation and participants are very proactive in discussing options and comparing notes. Among positive women, there can also often be discussion about the implications of treatment for body changes. Thus, even if most study participants did not actively seek out information, we know that positive heterosexuals take the opportunity when it arises in settings that are considered safe and anonymous.

HIV-negative partners, who were often even more disengaged from the HIV community, also claimed little interest in keeping up with information about treatment. However, most partners had set about educating themselves more broadly about HIV when they had first met their positive partner or when their existing partner had been diagnosed. In so doing, their primary source of information had been their own partner, followed by their partner's doctor and *Talkabout*. We also know generally that negative partners, particularly women, are frequent users of the Pozhet free-call line. While they often have a tacit agreement with their positive partners not to intervene in treatment decisions (see previous section), it is not uncommon for them to privately seek advice and reassurance.

As time went by, most negative partners came to view information as relevant or necessary only if things changed, for example if their positive partner was given a new HIV drug or became ill. Beyond that, knowledge was typically seen as the responsibility of their positive partner and their doctor. 'Ultimately he has a lot of faith in his specialist. And so do I' (Claire, aged 40). While neither negative nor positive participants subscribed to the neoliberal discourse of the informed, active health consumer, the vast majority were greatly invested in medicine. As discussed in the next two sections, most expressed a strong commitment to treatment adherence and to continued treatment in the future.

Adherence and dosing

Most participants described themselves as highly adherent to their treatment, though few used this term, instead using expressions such as ‘very religious’ and ‘compliant’ (a now outmoded term). This theme is consistent with their generally strong faith in and reliance on medicine. It also suggests their limited contact with the HIV sector

‘I lie to myself, “I’m healthy”, but I still have this virus in my blood. If I want to forget, I can’t forget [the medication]. If I forget [HIV], it means I will forget my medication, and if I forget my medication there is problem.’

and with peers, which might otherwise have exposed them to alternative discourses of living with HIV. Although they emphasised the importance of adherence, their experiences of dosing and its perceived impact on their lives were diverse.

About half the participants said that they did not find their dosing regime difficult. Many had been on treatments for years. They described the daily practice of dosing as a ‘part of life’, a ‘main priority’, a ‘two-minute thing’ and ‘not much of a chore’. Routine, acceptance and detachment were common themes. Olivia, 33, explained that daily dosing had become normalised over time:

It was a big deal when I first went on them. Like it was a huge hurdle for me to get over thinking: ‘God I have to take these things every day and twice a day.’ You know, ‘I’ve gotta take them wherever I go and I’ve gotta do this and I’ve gotta do that.’ But now it’s just kind of normal. It’s weird ... I don’t know. It’s just become that way.

The other half raised a number of difficulties with dosing. Those on regimes that involved food directives mentioned the complexity of managing the timing and practicality of dosing. Meagan, 47, spoke of the ‘excruciating pain’ of injecting Fuzeon due to her lipodystrophy.⁵ Fatima, 32, found it hard to adhere to her medication during the Islamic holy month of Ramadan, because the obligatory practice of fasting meant she had to take ART on an empty stomach, which made her feel sick. Narayan, in his 30s, was illegally in Australia and had to import his drugs from

overseas. Adherence was complicated for him by his drugs repeatedly arriving late, which caused him to miss doses. As a result, his virus had become resistant to several classes of HIV drugs.

Several mentioned ‘remembering’ as the main challenge with dosing. For some, it involved the difficulty of remembering to take the pills, especially during times of stress or competing concerns in their lives. Others found the act of dosing challenging because it reminded them of HIV (Sankar et al., 2002, Roberts & Mann, 2000). Corey, aged 48, said: ‘So it’s a reminder every morning and every night when you go and get those tablets out, you know, you’ve got a disease or a virus, or whatever. I think that’s probably the worst bit.’ Similarly, Mahmoud, 32, explained:

I’m really good with switching off; that I don’t have any HIV or anything. That’s how I tackle this. I pretend that I don’t have nothing. I’m just living normal. And it’s working quite well. But just when I take that medication in the morning and at night, I think about it. But just for a little bit.

This aspect of ‘remembering’ posed a particular predicament for those who, like Mahmoud, wanted to forget they had HIV. Treatments facilitated this ‘forgetting’ by suppressing the virus and keeping them symptom free. Their ability to forget HIV was therefore predicated on their ability to remember to take the medication. But their ability to remember to take the medication was, in turn, predicated on remembering that they had HIV. Fatima, 32, explained this dilemma:

I lie to myself, ‘I’m healthy’, but I still have this virus in my blood. If I want to forget, I can’t forget [the medication]. If I forget [HIV], it means I will forget my medication, and if I forget my medication there is problem.

The participants mentioned other ways in which adherence to daily medication impacted on their lives, including on their ability to travel, particularly to countries that prohibited the entry of positive people. Few were prepared to risk smuggling their medication through customs. Some who came from such countries felt unable to visit their families. It was doubly difficult if they had not disclosed their HIV status to their family and had to regularly invent excuses for not returning home to visit. Amoz, 58, said: ‘I’d like to travel. But this is hindering me. You know, they ask me questions. That’s what really bothers me. I feel like trapped.’

Others felt that their dosing schedules impacted on their ability to be socially spontaneous, as visiting friends or going out required some planning. Some felt restricted socially because of concerns that dosing would attract attention or questions and accidentally disclose their

⁵ lipodystrophy = unusual fat redistribution caused by particular HIV drugs

status. A few said that the greatest impact of daily medication was financial, particularly those who were taking a number of additional drugs and those who did not have a regular source of income because of their illegal immigrant status.

Most negative partners did not feel that their partner's daily dosing regime had a great impact on their lives. As with decisions about treatment, adherence and dosing were seen as largely the domain of their positive partner. But some women stated that they had been more active earlier in their relationships in helping to remind their positive partners to take their medication. Being involved in the daily management of HIV was seen as a way to show their partner support and acceptance, but it tended to taper with time. The generally strong emphasis on adherence among positive participants was another reason that negative partners felt there was little need to be involved in dosing regimes. Alice, aged 23: 'Sometimes I remind him but most of the time he remembers anyway. He's pretty good with his medication. Hardly ever misses a dose.' Similarly, Maria, 55, explained:

He's *highly* compliant. He's got perfect compliance. I've never seen him, only rarely, maybe once a year he'll forget because something's happened. He's not shambolic; he's *highly* disciplined around it, which is fabulous from my point of view because I haven't got to worry about it ... I think I would go mad if I was with someone who was all over the shop with their treatments, you know, with their compliance.

Closer involvement by negative partners in dosing regimes was noted among only a few couples in which the positive partner's degree of illness, or lifestyle, was perceived to be jeopardising adherence, or 'taking control' was seen as a way to manage the shock of a partner's diagnosis. These women felt compelled to keep an eye on dosing because their positive partners either kept irregular work hours that prevented a stable routine, or else were in very poor health due to a late diagnosis and being on a number of medications with complex schedules.

Treatment breaks and the future

Many participants had been on different combinations of drugs, particularly those who had been positive for a long time. Side effects and allergic reactions were the main reasons for a change of combination; other reasons were viral resistance and, to a lesser extent, the availability of new drugs with easier dosing regimes. But few had had any substantial treatment breaks or 'drug holidays'. Most had remained on ART more or less continuously since

they had started. In this respect, the findings differed from the HIV Futures survey, which found a relatively high occurrence of treatment breaks among a sample of predominantly gay men (Grierson et al., 2004) and women (McDonald et al., 2005). But the findings are consistent with recent scientific advice against episodic treatment (The SMART Study Group, 2006).

When treatment breaks did occur, they tended to be unintentional or an upshot of difficult life circumstances, such as substance abuse, depression, death of a partner or not being able to access ART through Medicare due

[T]here was a sense of not wanting to push one's luck with a treatment break ...
'I've had the virus now for 22 years. So I shouldn't play with it. While you're on a good thing you have to stick to it.'

to illegal immigrant status. Some had also experienced unwanted treatment breaks when in hospital, as a result of medical investigations or a drug being temporarily unavailable. Only a few had purposely discontinued treatment, largely due to debilitating effects, but had later resumed ART when their health began to deteriorate or when better medication became available.

The prospect of having a treatment break was not widely entertained. Only three participants, all women, said they intended to have a break in the future, mainly to 'clean out the system' due to concerns about the long-term effects of ART. 'It's very strong medication', as Fatima, 32, noted. Two-thirds were expressly opposed to the idea of having a break, while four said they would like to have a break but did not consider it a realistic option. Most were generally resistant to the idea of tinkering with their treatment in any way.

Firstly, there was a sense of not wanting to push one's luck with a treatment break. Antonio, 71, explained: 'I've had the virus now for 22 years. So I shouldn't play with it. While you're on a good thing you have to stick to it.' Similarly, Mahmoud, 32, said: 'I'm doing good and I want to stay doing good, so I don't want to, um, muck around with it, you know.' And Olivia, 33, put it this way: 'I've been on them for so long and had so much success with them that I just want to keep riding that. I guess I've been lucky on that front.' Sticking to successful treatment provided a certain sense of security and reassurance, whereas a treatment break was associated with the unknown:

I read that, about a few people doing that. It doesn't cross my mind, to be honest ... I don't want to take a leap in the dark, you know. If I stop, what happen? Something will develop, or something. You know what I mean? ... No, to be honest, I'm chicken with that. I didn't venture to think about it. Until further notice maybe, until some other discovery or something, I will. But as it happens, I just, you know, do what's written, as such.

(Amoz, aged 58, diagnosed 2000)

There was considerable concern about what would happen if they stopped treatment even for a short period of time. Many were convinced that their health would be adversely affected. 'I think if I stop I get sick very quickly', Antonio said. To emphasise this point, some relayed stories about other positive people they knew or had heard of who had experimented with treatment breaks with supposedly disastrous consequences. For Grace, aged 66, seeing the effects of HIV on her husband made a treatment break a daunting proposition:

That might be a bit frightening because I see how Gordon has gone. Because he had it 10 years before he was diagnosed ... And that would really frighten me to think that I would go the same way ... I think I'd be a bit scared. Because I know all the frustration that Gordon goes through. And I think, 'Oh, no.' It's too much stress and frustration *now* without going and doing that as well. So I think I'm better off staying as I am and staying on the tablets.

Concerns about the impact on health of a treatment break were particularly pronounced among those who had experienced HIV-related illnesses in the past or who had presented late with an already impaired immune system. Having a break was not seen as an option for them. Dean, 49, explained that he was 'well into AIDS territory' before starting treatment in 2004 and that he would end up very sick again if he had a break:

What options do I have? ... These are serious chemicals, you know. You wouldn't take them if you didn't have to. But I don't think I have any choice. I think treatment breaks—I haven't had good enough evidence about them.

Like Dean, some participants referred to scientific research on treatment breaks. Tobias, 53, explained his decision to stay on treatment: 'I follow medical science ... The best medical advice is to do what I do.' Similarly, Antonio claimed that 'they had a trial and [in] the trial they find out that it's not wise to have a break'. Several participants also said their doctor had never broached the subject of treatment breaks with them. With few exceptions, those who had themselves initiated a discussion about breaks said their doctor had advised against it:

I asked [my doctor] if it's all right to have a holiday from the tablets. He said, 'No, they don't recommend it. Just keep taking them' ... Apparently it's not possible. So, it's not a good idea. Because they say, you know, if I *do* stop them, it might increase its strength. The virus, yeah.

(Gordon, aged 61)

Others framed ongoing medication as a necessary and commonsensical response to having a serious illness and as a normalised part of everyday life. Meagan, 47, said: 'That's life. Other people have to take medication for other things ... It's just the way it is. And you accept it.' Along similar lines, Ratu, 43, explained why he was not interested in having a treatment break:

Taking medication doesn't bother me ... I'm the kind of person, if I have to take medication I'll take it. To me it's not a hassle. Maybe to some people it is, but to me it's not a hassle at all. It's just something I have to do, you know. Go with it ... I'm thinking, you know, what is the reason? Why do I have to take a break? Because I'm taking it for my benefit ... I don't see any logic in it ... To me, it's part of my life.

A strong preference for uninterrupted treatment was common also among negative partners. Nobody wanted their positive partner to discontinue treatment or have a break. Their reasons were similar to those of the positive participants, revolving around the themes of necessity, inevitable illness and not needlessly tempting fate. Maria, aged 55, said: 'There is *no* alternative to taking them and taking them as they have to be taken.' Claire, 44, stated: 'It's working, so why stuff around with it?' Similarly, Katya, 52, reasoned:

I think it is better for him to take them than to stop them. You know, like, in that way like he can be reasonably OK. You know, like if he stop them, maybe in two or three weeks time he go back [to] the start ... So no, it's not good to stop.

The idea that ART enabled normality was also a strong theme in some partner interviews. There was a sense that medication not only suppressed HIV in the positive partner's blood, but also erased it from everyday life. Lowanna, 25, was one of few partners involved in treatment decisions. She relayed a discussion with her partner after his HIV specialist had suggested that he stop ART for a clinical study:

'No. I don't want you to. *Why* would you want to go off something that's making you so healthy? Making you have undetectable, you're undetectable. It's like it's not even there, you know? It's like a ghost in your body somewhere ... Why would you want to do that?' I said,

'That's insane.' I said, 'No. For me, I wouldn't like you to do that for all of our sake, you know, for your own health and for our, for this family.' I said, 'We live every day like you don't have [HIV]. Why would we want to turn that around?' You know, like have to go through when he gets sick or if anything was to happen ... I never want him to go off the treatment.

Many positive participants said they would stop treatment only if their doctor advised them to. Several also stated that they would consider a break if they were travelling to countries with immigration laws that banned positive people from entering, particularly the US.⁶ Some who received the disability support pension said they would stop treatment only if ART were removed from the Pharmaceutical Benefits Scheme, because they would not be able to afford it. Three said they would stop if the treatment made them sick or if detrimental effects outweighed the benefits. Another two would cease treatment if God told them to or cured them of HIV. And one man, who was illegally in Australia with no access to Medicare, said he would stop treatment only if, for financial or logistical reasons, he could no longer import his HIV drugs from overseas.

The overwhelming majority were resigned to staying on treatment forever. Some, like Carlos, aged 37, said it did not worry them: 'I think I've very much accepted the fact that I probably will have to take medication for the rest of my life ... I've been taking the treatment for so long now, it's just become a part of my life and it doesn't affect me.' Or as Ratu, 43, joked: 'I've gotta go to the toilet for the rest of my life. And that's worse.' Others said that while they did not like the thought of having to take ART interminably, they accepted it and tried to put their situation into perspective, including Corey, aged 48:

I don't like it. But it could be worse. You could be in a wheelchair. You could be, you know, a vegetable in a bed. I suppose popping a few pills morning and afternoon or morning and night is better than having insulin that you've got to inject, and doing blood tests every so often with your fingers. So, you know, by comparison I think it's a reasonably mild interruption to life [compared] to what other people have to go through.

Dreams of a future free of HIV were, for many, the flipside of their commitment to lifelong treatment. Both men and women expressed hopes for a cure or for medical advances that would further streamline ART. 'I'm hoping for newer and better treatments. I mean I guess everyone hopes

for a cure' (Ellen, 45). Some anticipated that progress would be made in stem cell research and other scientific technologies that would benefit positive people by turning HIV into a trivial virus, or by ultimately eradicating it. 'That's my hope, before I leave this world. I like to leave it as I came,' said Amoz, aged 58. Alongside such hopes, four men said they intended to commit suicide if they ever developed AIDS. 'I'm not gonna die hideously of AIDS,' argued Tobias, 53. Similarly, Victor, 34, said:

I've always said that if I can't maintain a lifestyle down the track, if it gets that bad that, you know, family and friends have come to see me in hospital, I'll end my life with dignity. I will kill myself. Not afraid to say that ... Hopefully that time will never roll around but, you know, that's the way I personally see it.

Whatever their fears or hopes for the future, most counted themselves lucky to be HIV-positive in a country such as Australia with access to government-subsidised medications and world-class health care. Several participants made reference specifically to the HIV crisis in Africa, saying, 'It's just not the same disease here in Australia.' While such a comparison tended to be used as a narrative device to 'minimise' the gravity of having HIV, it was a reality for those who came from countries with little or no HIV care. Fatima, 32, who was from a sub-Saharan country with a high prevalence of HIV, explained that going back to her country was not an option, because 'I will die'. The future was uncertain for another two participants who were currently illegally in Australia and who feared having to return to their home countries where positive people were highly stigmatised and had little access to treatments.

Efficacy and side effects

Although the participants were generally strongly committed to treatment, their experiences of taking ART were by no means uncomplicated. Research has shown that feelings towards treatment are often ambivalent. One reason for this is that supposedly objective medical information is frequently contradicted by subjective experiences. Patients may be diagnosed as sick when they feel good. A blood test may indicate that they are healthy when they feel unwell. Or the drugs that are supposed to keep them healthy may make them *feel* sick (Race, 2001; Persson et al., 2003). How people experience and negotiate the effects of treatment is mediated by their understanding and expectation of ART. Taking medicine involves more than the physical ingestion of pills for remedial purposes. Embedded in and embodied through this act are cultural ideas about self and body, about illness and health and about efficacy and priority (Nichter & Vuckovic, 1994; Persson, 2004).

6 The US senate recently voted to repeal this ban, see: <http://www.alertnet.org/thenews/newsdesk/IRIN/224f7903200f105dc7ab1059869da323.htm>

Indicators of efficacy

The standard clinical method to assess the efficacy of ART is a regular blood test that measures viral load and CD4 count. An undetectable viral load is generally seen as the aim and clinical marker of successful therapy and, as such, has become a common criterion by which HIV health is conceived (Race, 2001). Yet, when asked how they personally ascertained or knew that their medication was or was not working, the participants drew on multiple frameworks and indicators. Most mentioned a combination of feeling states and clinical markers as signs of efficacy, but many tended to place more emphasis on one or the other, a pattern that was interwoven with biographical themes.

Those who had been extremely ill, near death, or positive for a long time often focused on subjective feelings of health. Being alive, having a good appetite and not feeling unwell were frequently mentioned as indicators that their HIV drugs were effective. Gavin, 48, who had presented

‘Basically a feeling of ability to cope ... with day-to-day life, the idea of shopping, the idea of working ... And to be able to cope with that I’ve got to be completely functioning well. Or function at least 75% ... That tells me the drugs are working.’

late with a number of health complications, said: ‘The way my body feels ... It’s something you can actually feel. I can actually *feel* that they are working.’ For Meagan, 47, who had been positive since the mid-1980s, having the energy and capacity to live her life was her indication that treatments worked:

Basically a feeling of ability to cope; I’m able to cope with day-to-day life, the idea of shopping, the idea of working ... And to be able to cope with that I’ve got to be completely functioning well. Or function at least 75% ... That tells me the drugs are working.

Kevin, aged 58, who had been gravely ill when combination therapy arrived, said that being alive was his evidence of the efficacy of treatment: ‘I guess when I started to come well, well then I realised, you know, the drugs are working. Because if I didn’t have them, I wouldn’t be here now. A lot of us wouldn’t be here.’ With a continually low CD4 count and a recent rise in viral load, his test results were not ideal from a clinical perspective. But Kevin’s assessment of efficacy pivoted not on clinical markers so much as on a comparison between his life

before and since treatments: ‘They’re working because I can live again. Whereas before I was really [only] existing ... Just that it feels like life is normal again ... I’m just steady, you know. So they are working.’

Those who had not experienced any HIV-related illness tended to place more emphasis on an undetectable viral load as the most significant indicator of the efficacy of treatment. Grace, 66, said: ‘I just rely on what the doctors tell me. And they tell me everything’s going OK and is fine. And the viral load’s good. And everything’s undetectable. So that’s what I go by ... That’s my indication.’ Some explained that their clinical markers had rapidly deteriorated when temporarily off treatment only to dramatically improve again when they resumed ART. To them, this was a clear sign that the treatment was doing what it was meant to be doing. Mahmoud, 32, recalled the effects of a one-month treatment break when he was in prison:

My viral load went to like, you know, how they read it in millions and all that? Yeah, it [went] from undetectable; it went to millions ... I actually got a rash, yeah, the rash that I first got when I first contracted HIV. So an outbreak again of it. So it’s like I got infected again, you could say. Yeah? Because the medication, like, I mean, I feel like that it’s suppressed [the virus]. And it hasn’t allowed it to go anywhere. But as soon as I stopped [the treatment], it just went ‘vroom’. It just hit the roof.

There was considerable investment in the idea that ART had the power to immobilise the virus. Olivia, 33, explained why she felt her treatment was effective: ‘My viral load has been undetectable for that whole time and I *like* it that way ... I like the fact that it’s probably stuck away in its little hidey hole and that’s where it’s stuck [laughs]. And I want it to stay stuck.’ For some, an undetectable viral load was not only a marker of the efficacy of treatment but also an essential criterion. Carlos, 37, said that because of his ‘devotion’ to his medication, he expected it to work optimally:

Unfortunately my viral load is just above detectable and has been like that for 12 months, which, it’s unacceptable for me ... I’ve become used to being undetectable and I’ve become very demanding on my body with respect to my health. So I’m getting my medication changed, again with the hope that it will bring my viral load right back down to undetectable ... They’ve been working for me all these years so I have no choice but to believe in them ... So I want that to get back to *normal*.

As this quote suggests, an undetectable viral load was often equated with normalcy, a theme closely tied to treatments as discussed earlier. Having an undetectable viral load

carried the possibility of seeing oneself as not all that different from the mainstream: 'If it's undetectable I feel a bit comfortable with that,' said Amoz, aged 58. 'I mean I'm almost OK, you know, like any other normal guy.' In this sense, effective treatment was indicated not only by favourable clinical markers, but also by a reassuring sense that nothing had really changed since diagnosis. Mahmoud, 32, explained why he took a keen interest in his test results:

It's important. I check my blood test. Oh my God, if I don't see my blood test, I won't be happy. I won't leave the doctor's surgery 'til he shows me the blood test. My CD4. I just want to find out [about] my liver, my everything ... I'm really into it, you know ... [It is] very comforting, yeah. Because when I see that result I feel, 'Wow. Yeah, still the same. *I haven't changed.*'

Negative partners often interpreted the efficacy of treatment in similar ways. If their positive partner had been extremely sick or dying, then well-being or an absence of illness tended to be the primary concern when assessing successful treatment, while an undetectable viral load was often prioritised among those whose partners had not been ill. The association between the efficacy of treatment, an undetectable viral load and a normal life unchanged by HIV was also found in some interviews with partners:

It's like he's getting cured, like it's going out of his body or something ... I *never* think, like he doesn't get sick ... See, I forget he's got HIV and I forget he's on these extreme medications ... Like if they go, 'It's undetectable,' yes it's still there, but I just, I just get this feeling all the time of he just doesn't have it.

(Lowanna, aged 25)

One Australian survey found that positive women had less faith in the efficacy of treatments than other population groups in the epidemic (McDonald et al., 2000a). This was not the case in the Straightpoz study where men and women expressed a similar confidence in treatments. But one theme that was quite prominent among the women was the significance of side effects in assessing the efficacy of treatment. Several women described their personal indicators as a combination of clinical markers and an absence of side effects. Lydia, 44, explained why her current combination was successful where previous ones had fallen short: 'This combination that I'm on seems to be working. Like I said, no side effects, no shingles in the eye, no fits, no anaemia, no shakes, no hair falling out.'

Negotiating side effects

Almost all participants had experienced adverse effects of treatment. After diarrhoea, body-shape changes were the most commonly mentioned side effects, with two men and three women having lipodystrophy, and two men and one

woman having significant weight and muscle loss. Another four reported allergic reactions to particular drugs. Three men had had heart problems due to increased cholesterol levels, with two having had a heart bypass. Four described

Body-shape changes emerged as the most confronting and difficult side effect to manage, not just physically but, even more, emotionally and socially. These challenges were often intimately bound up with HIV itself, with treatments playing an ancillary role.

vivid dreams and nightmares, a known effect of efavirenz (Persson & Newman, 2006). Other documented adverse effects (Carr & Cooper, 2000) were mentioned by one or two participants, including peripheral neuropathy, nausea, kidney problems, anaemia, sleep disturbances and reduced memory.

The most common strategy in response to significant or enduring side effects was to change medication. But this was not always possible and in some cases the effects were chronic or irreversible and therefore had to be managed in some other way. A few participants had taken Imodium for years to manage persistent diarrhoea. Others had resorted to dietary methods and fish oil supplements to reduce their cholesterol levels, and one man had experimented with herbs to help relieve peripheral neuropathy. Two participants with lipodystrophy had had Newfill injections into their cheeks and temples to reduce the effects of facial wasting. One woman had also had liposuction on her neck and torso, but with short-lived results.

During the interviews, participants were given opportunities to discuss how they felt about side effects and whether or not such side effects affected their feelings about treatments. Most said they were prepared to accept side effects if they were minor, transitory or introductory when weighed against the perceived benefits of the treatment:

I think a little bit of nausea maybe for a week or—and that is worth it. Because this is what is, can help ... [It's] keeping me as healthy as I can be with what I've got. So that's how I've kind of looked at it. Having to weigh up the pros and the cons.

(Lydia, aged 44)

Those who had been positive for a long time were often resigned to side effects being a part of treatment and the price of survival. They described them as something they had to accept and manage or, as Kevin, 58, put it: 'I mean,

you learn to live it.’ Like Kevin, Meagan, 47, had had a long treatment history and several major side effects, including lipodystrophy and chronic diarrhoea. When asked if these effects had an impact on how she felt about treatments, she replied: ‘Not really, because the bottom line is that I’m alive. And I’m well enough to work ... I just accept it as being something I’ve gotta put up with.’ Victor, 34, who had not started treatment, also framed side effects as an acceptable price for more imperative objectives: ‘I’ve read about lipodystrophy and those sorts of things. But, look, I’m prepared to take that gamble. It’s better than getting AIDS, in my eyes.’

Given the participants’ strong reliance on medicine, it was perhaps unsurprising that side effects tended to be de-emphasised. Participants’ general disconnection from communal forms of support and dialogue around HIV might also explain why side effects were so often endured and managed in private, rather than being shared or politicised. Yet, there was a sense of gratitude towards the gay community for having fought those battles for access to treatments and for better drugs. Although scepticism of pharmaceutical companies was raised by a few, mostly men, when discussing side effects, there was often little criticism of the treatments themselves.

However, there were some participants for whom a different set of priorities shaped negotiation of side effects. Brendan, 48, was one of the few who did not frame ART as a key strategy for managing HIV and creating a

‘I’ve had to go along that thing with him. Watching him change. It’s very painful ... It’s part of the loss, the sum total of loss of HIV ... And the thing that’s doing it is the thing you’re dependent on to stay alive.’

sense of normality in his life. For him, side effects were unacceptable and not worth the potential benefits. This became particularly clear when, determined to recover from a drug relapse, he experienced side effects while also trying to cope with withdrawal symptoms and caring for his young daughter. He decided to stop taking his medication when he felt his repeated complaints to his doctor went unheard:

They had me on these orange things. I kept telling them for months and months, and months. ‘Listen, these things are making me sick. I’m not gonna fucking take them anymore.’ Used to give me fucking bad nightmares and vivid nightmares. I just said to them, ‘Listen, ey, I’ve got enough fucking problems with my head without making them vivid!’ ... Horrible fucking things ... I

just didn’t take ‘em. And about, I don’t know, I seen me doctor 12 months later ... And he said, ‘How long since you took medication?’ I said, ‘Oh, about a year ... I kept telling you people that these things were making me sick. I’m not taking them.’ And they switched the pills to these new ones.

For Sabrina, 46, avoiding facial wasting was more important than an undetectable viral load. She had been diagnosed with the rare K65R mutation, which meant that her HIV was resistant to most classes of ART. She said that ‘the only drugs that I’m not resistant to are the ones that give me the lipoatrophy.’⁷ I don’t want the lipoatrophy.’ Her doctor had urged her to change her treatment to try to suppress the virus. But despite a high viral load and a chronic feeling of fatigue, she preferred to stay on her old combination:

Because my doctor said that if you go off it you will get worse. But at the moment it’s still keeping the virus a little bit unfit ... I said to him, ‘Well look, it’s not, I’m not gonna drop dead tomorrow’ ... So I’m choosing at the moment to stay on these. I prefer to spend half my life horizontal than—and get up and have a full face.

Body-shape changes emerged as the most confronting and difficult side effect to manage, not just physically but, even more, emotionally and socially. These challenges were often intimately bound up with HIV itself, with treatments playing an ancillary role. Changes in body shape were experienced as an exterior manifestation of HIV and thus worked against the notion of ‘normality’ by making the previously hidden stigma and reality of the virus visible to both self and others (Persson, 2004; 2005). Kevin, 58, hid his facial wasting behind a beard: ‘I’m always conscious of that ... The AIDS look, you know. I’m scared of that, having that.’ Tobias, 53, recalled his reaction when told he had early symptoms of lipodystrophy: ‘I got very upset and started to cry ... “I don’t want to die of AIDS.”’ Maria, 55, described her husband’s lipodystrophy as a physical insignia of the losses brought about by HIV:

That is really, really hard [starts crying] ... I’ve had to go along that thing with him. Watching him change. It’s very painful ... It’s part of the loss, the sum total of loss of HIV. The loss of work life. The loss of intimacy with other people. The loss of community and so on. The loss of the body. The loss of the illusion that you have control over your body ... And the thing that’s doing it is the thing you’re dependent on to stay alive. So you have to accept it ... It’s a *huge* paradox ... And so because in an unspoken way we understand all of that, we accept that this is the price you pay.

⁷ lipoatrophy = wasting of fat and muscle as a side effect of some antiretroviral drugs

As Maria's quote suggests, side effects of treatment had an impact on negative partners as well. Some spoke of how helpless they felt watching their positive partner suffer. Others said that their positive partner tried to protect them by concealing or denying adverse medical effects, which sometimes caused confusion and tensions in the

relationship. Maria's quote also hints at the isolation felt by many heterosexuals living with HIV. This was highlighted by a number of participants who expressed a desire to reach out and find safe ways to share their experiences with peers, especially around coping with bodily changes.

2 Health

Biomedical constructions of health and illness as natural, objective categories have long been challenged by social research, which brings to the fore how experiences of health are infused with social, cultural and biographical meanings that repeatedly contradict and escape the confines of biomedical models (Frank, 1995; Kleinman, 1988; Toombs, 1992). These meanings tend to incorporate bodily symptoms, feeling states and broader notions of well-being based on degrees of emotional, social, or spiritual fulfilment. At the same time, for many people with HIV, biomedicine is a consequential part

For positive participants, HIV was rarely their only, and not always their most critical, health condition. However, many of their conditions were directly or indirectly related to having HIV or to treatments.

of their lives. It operates through particular discourses and technologies whereby their health is gauged and therapeutically managed and, indeed, upon which their health decisions may vitally depend.

Breakthroughs in the treatment of HIV, and its ensuing redefinition as a 'chronic illness', have compounded the ways in which HIV is understood and lived. This, together with the uncertainty that characterises many chronic conditions, makes problematic any easy construal of HIV in terms of health or illness. Some people speak of readjusting to the idea of suddenly having a future, of regaining their health. For others, periods of feeling unwell alternate with periods of feeling well. Those who have never experienced any HIV-related symptoms may describe daily medication and regular visits to a clinic as paradoxical signs of illness in an otherwise healthy life (Persson et al., 2003). At the same time, the stigma surrounding HIV may have its own corrosive effects on health. It is within these socially embedded contexts that HIV 'health' must be interpreted and understood, not only as it pertains to those infected, but also as it pertains to those who share their lives.

Illnesses and medications

For positive participants, HIV was rarely their only, and not always their most critical, health condition. However, many of their conditions were directly or indirectly related to having HIV or to treatments. Those who had been positive for some time described a range of major and minor health issues, such as lipodystrophy, neuropathy, diabetes, weight loss, fatigue and problems with the heart, skin, kidneys, liver, oral health and recurring viral infections, such as herpes, shingles and Bell's palsy. Two men had had a triple bypass, one man and one woman had mild dementia and one woman had advanced cervical intra-epithelial neoplasia (CIN3). Some late presenters experienced ongoing complications from opportunistic infections such as pneumocystis pneumonia (PCP) and progressive multifocal leukoencephalopathy. Several participants also reported age-related health issues, which can have an early onset in people with HIV, including arthritis, osteoporosis and menopause.

Not all of participants' health conditions were related to having HIV. Four men and one woman also had hepatitis C and another man had hepatitis B. One man had hereditary heart problems and another had Hodgkin's lymphoma. Three participants reported spinal impairments and two had asthma. Four men and two women described mental health problems, including depression, anxiety, panic attacks, bipolar disorder and obsessive compulsive disorder. Mental health issues often preceded the HIV diagnosis, though several felt the diagnosis had worsened their symptoms. Most stated that their mental health problems had a much greater impact on their lives than HIV. Another two participants said they had been diagnosed with depression by their doctor, but resisted this diagnosis. Eight, mostly men, described past or ongoing drug and alcohol abuse, which again often overshadowed other health issues including HIV.

Given these myriad health problems, many participants were taking medications in addition to ART. Six were on prophylactic antiviral, antifungal and antibacterial

medications. Seven were on antidepressants, though two had been prescribed these to help manage insomnia and peripheral neuropathy. Several took medication for gastric reflux, chronic pain, osteoporosis and for their heart and cholesterol, while two women were on hormone replacement therapy and three men smoked marijuana to increase their appetite or to reduce stress and sleep difficulties. Several participants were also taking vitamins, herbs and supplements for general health, as well as to aid specific issues, such as fish oil for joint pain and high cholesterol and naturopathic herbs for fertility problems and peripheral neuropathy.

Only one participant had had treatment for hepatitis C and had cleared the virus. Of the other five participants with hepatitis C, two were reluctant to seek treatment because they did not want to take more medications and had also heard ‘bad things’ about the side effects of interferon. One man said that he did not know enough about the treatment to make a decision, while another man wanted to go on treatment but was reluctant because it might require him to take time off work. Angus, 53, who had had hepatitis C for 30 years, did not have a genotype that responded well to treatment and therefore did not think treatment would be worth the side effects. None reported any symptoms associated with hepatitis C, except for Angus who experienced sporadic nausea.

Current health status

Despite often having a number of health issues, most participants rated their current state of health relatively highly. Three-fifths described their health as ‘pretty good’ or ‘good’, while a fifth said their health was ‘very good’, ‘excellent’ or ‘amazing’. Only a fifth described their health as ‘bad’, ‘not good’ or ‘shocking’. Length of time since diagnosis played little part in how the participants rated their health, and the relationship between physical symptoms and descriptions of current health status was not always straightforward. But what was notable were the ways in which HIV figured in their assessments of health.

Some participants saw their health as no different from what it had been prior to their diagnosis with HIV. Any symptoms of illness were interpreted as part of the ordinary range of afflictions within the general population rather than necessarily specific to people with HIV. ‘I really honestly don’t get any health things that I wouldn’t have if I wasn’t positive,’ stated Lydia, aged 44. ‘I don’t get anything different to, than I did seven years ago.’ Amoz, 58, said: ‘Occasionally I just lose appetite or something like that ... I keep telling myself, maybe everybody could have those things, you know. Anybody could have them. Not particularly me.’

Several participants described their health favourably in relation to their age, rather than in relation to HIV. ‘Pretty good for a 53-year-old bloke,’ as Tobias put it. Antonio, 71, had been positive for over 20 years, had lipodystrophy and kidney problems and had also had several heart attacks. When asked to describe his current health, he replied: ‘Well, I can’t say excellent but I say it’s good, I mean for a person my age. I wake up at half past six in the morning. I cook breakfast. Have a shower. Feed the birds. Water the garden. Prepare for the gym. I go three times a week to the gym. And I exercise two hours.’

Some, mostly men, gauged their health by comparing themselves favourably to other people with HIV.

Mahmoud, 32, described his health as ‘excellent’, emphasising his difference from other positive people: ‘I’m living different than other people that’s got the same virus; they’ve gone really—I hate saying that—like I mean, really worse than I am. Their health has deteriorated, you know.’ Brendan, 48, experienced major eating problems, weight

‘I suppose I try to kid myself sometimes that I don’t even have anything because I look so healthy ... probably because I see myself as being so healthy and my partner hasn’t got HIV, and none of my friends have HIV, so I’m nearly fooled into thinking that it’s not a part of my life even though I’m taking medication every day.’

loss, mild dementia, liver problems and had had shingles ‘in me head’ several times. Yet he stated that his health was ‘pretty good actually’ and invoked a discourse of masculine hardiness by describing how other people seemed more affected by HIV than he did:

I look at everybody else that either has the HIV or the, or is completely gone to AIDS. And they’re pretty much immobile. They don’t seem to do much. They don’t seem to go anywhere. They don’t seem to be very active, whether it’s just around the house or whatever ... It’s like they’ve got the weight of the fucking world on them. And I think, ‘It can’t be that bad.’ It can’t be any different for them than it is for me, surely.

Others similarly emphasised their robustness in the face of HIV by pointing to the absence of any symptoms of illness and to their doctors’ marvel at their clinical markers. Victor, aged 34, who was diagnosed in 2003, said he gave

himself ‘a pat on the back’ for not having needed to go on ART: ‘I’ve got an exceptionally high CD8 count, which is another sort of fighter cells alongside the CD4. Doctors have been quite amazed at how strong my CD8 count’s been all along ... Liver, kidney functions, electrolytes; everything has been outstanding.’ Along this theme, some underscored how healthy they were by suggesting that they were tempted to think they did not really have HIV, as Carlos, 37, explained:

I suppose I try to kid myself sometimes that I don’t even have anything because I look so healthy ... But I guess it’s, looking into it as honest as I can, I find that probably because I see myself as being so healthy and my partner hasn’t got HIV, and none of my friends have HIV, so I’m nearly fooled into thinking that it’s not a part of my life even though I’m taking medication every day. But it’s very easy for me to fall into that trap because of how healthy I feel.

A contrary perspective was provided by participants who said that having HIV meant having bad health. For some, this assessment of health was directly linked to symptoms of illness. Gavin, 48, had experienced a range of health complications since his late diagnosis in 2000. He described his health as ‘shocking’ and was highly critical of the discourse of ‘living a normal life’ as an HIV-positive person:

That’s rubbish ... It’s gotta affect you in some ways ... your life is never gonna be the same ... [T]he first counsellor I seen said, ‘You won’t even know that you’ve got it.’ I’ve never heard something further from the truth ... You know, it’s affected my life so much. You know, I can’t do the things I used to.

But others described their health as ‘bad’ simply by virtue of being positive. Corey, 48, had no symptoms of illness besides chronic pain from an injury. When asked to describe his health, he said: ‘I always say it’s bad. HIV-positive; that’s not good.’ Similarly, Fatima, 32, who was diagnosed 10 months before the interview, was asymptomatic and on treatments. Yet, because of her HIV status, she saw her body as weakened and vulnerable to illness and therefore, by definition, as unhealthy: ‘My body is open to everything now—welcome!’

These accounts seem to suggest a rather arbitrary relationship between symptoms of illness and descriptions of current health status. However, as noted above, ‘health’ is a phenomenon imbued with cultural and contextual meanings. How people assess their health is contingent on what they interpret ‘health’ to be and what it means for them to be ‘healthy’.

Definitions of ‘health’

The participants’ definitions of ‘health’ were diverse, yet the interviews were dominated by three key themes: feeling states, everyday functioning and life before diagnosis. It is interesting to note that, although they often volunteered information about their CD4 count and viral load during the interview, very few included clinical markers in their definition of health. However, effective treatments were often implicit in these themes, particularly when the participants’ health status matched their definition of good health.

Firstly, participants defined ‘health’ in terms of physical, mental and emotional feelings of well-being. They would use expressions such as ‘feeling healthy’, ‘not feeling sick’, ‘feeling good in your body’, ‘feeling physically well’, ‘feeling motivated’, ‘having energy’, ‘having a good attitude’, ‘having a good appetite’, ‘enjoying life’, ‘being happy’, ‘being fit’ and ‘being mentally stable’.

This definition was often subsumed within a second and more common definition of health that centred on cultural norms of day-to-day functionality and ‘doing’: ‘I suppose being able to live my everyday life, you know, getting out of bed without any aches and pains ... just, feel, and being able, I suppose, able to do everything’ (Ruby, aged 36). For many, health was synonymous with the ability and freedom to do what they wanted to do, as Ratu, 43, explained:

As long as I can do what I want to do, then I’m healthy. Once I cannot do what I want to do, there’s something wrong; I’m not healthy. Yeah. Now I can do whatever I want to do. So I see that as healthy.

There was an emphasis on normalcy in this definition of health. To be healthy was to be able to function, and to function was to be normal. When asked what health meant to him, Amoz, 58, said: ‘I guess it means that, you know, you’re a normal human being. You can function. You can perform your duties like a normal human being.’ However, those who had been positive for a long time had often had to adjust their criteria for ‘normal functioning’ over the years due to the effects of HIV and treatments. Meagan, 47, explained why her definition of health was different from that of other people:

I mean, to other people, health would probably be doing without a lot of the pain that I go through. But to me, I find it an acceptable part of the fact that I’m alive ... You’re right to ask what my definition of health is because it’s not the same as somebody else’s definition of health, which would be total well-being, ability to, you know, go and work out at a gym, or all of those things. That is not the case with me. I consider as long as I can do what I need to do when I need to do it, then I’m healthy.

Thus, for some, the definition of health as ‘normal functioning’ was uncoupled from any expectation that they should be able to do whatever they wanted in life and instead reinvested with more modest aspirations and everyday needs. According to this redefinition, which hints at resilience, they could still consider themselves healthy as long as they were able to do basic things, such as eat, breathe and perform simple domestic tasks without help or without too much physical difficulty. Angus, aged 53, commented:

Health to me is just being able to get up in the morning and eat. Be able to function. Yeah. Just being able to breathe properly without having to struggle for air in my passageways ... And being able to get out and just being able to still get up off my arse and walk up the shops. And carry my own shopping back without having to rely on taking someone with me to carry it. Yeah, and just being able to get up, walk out, hanging a clothes-line up. To me that's, yeah, being healthy.

The third and less common definition of health focused on life before diagnosis. Extending on the theme of ‘normal functioning’, health was defined by the extent to which life continued uninterrupted and unchanged by the virus. Thus, to be healthy was to feel and do the same as before diagnosis. Lydia, aged 44, explained:

For me, it's being able to get up in the morning and just — yeah, just to feel like I did before I got diagnosed. You know, like not have anything that could stop me from doing the things that I want to do with my life, whether it be going to the gym, go to dance class, travel, work, whatever. Just to be able to get up and live my life like I would before my diagnosis ... I mean, I can never be like what I was seven years ago, but trying to just keep that part of it going. And not, you know, not hopefully, you know, letting this virus have an impact on my health where it stops me from doing things I want to do really, yeah.

According to this definition, health was something that existed prior to diagnosis for those whose lives had been profoundly altered by HIV. For 48-year-old Gavin, illness, medications, hospital visits and poverty had marked his life since his late diagnosis in 2000. He saw his capacity for ‘normal functioning’ as very different from what it had been. When asked what ‘health’ was to him, he replied:

Don't know anymore [laughs]. It's been a while ... I can't do the things that I used to. I used to be able to lift up 125 kg from the floor and put it onto a table. I have trouble sometimes now lifting up the cat. You know, that's depressing ... I used to be able to walk 15, 20 kilometres with no problems. Loved it. Now I have trouble walking up the, walking to the corner store

... I'd love to go back to work and be fully employed again. You know, it's not only the financial thing; it's the interaction with other people. It's also feeling useful ... I'm just cheesed off that I can't do the things I used to do. Being able to do normal things.

One of the few definitions of health that departed from the western ideal of the functional and productive person was provided by Fatima, 32, who came from a sub-Saharan country. To her, health was ‘to be strong’, which she explained as the ability to prevent disease from entering the body in the first place. She said that she used to be proud of her health, because she was never sick and she never got malaria, which was rife in her country and had affected several family members. She speculated that, because she was so strong, she had gotten the ‘strongest’ disease, HIV. ‘Before I do not get anything, but when I get, I get bad one, strong one, the strongest one.’

Health management and perceived control

Under the political conditions of neoliberalism, there is increased emphasis on individual responsibility for health. Health consumers are positioned as informed, autonomous agents who possess the capacity to care for themselves and who are expected to protect and improve their health by actively engaging in rational lifestyle choices (Galvin, 2002; Peterson & Lupton, 1996). Self-efficacy and a sense of control have been identified as valuable coping strategies among people with HIV (Gifford & Sengupta, 1999). At the same time, the onus on individuals to take responsibility for their own health ignores the fact that many complex factors are at play in illness, which are often beyond individual control, and that choice and autonomy are therefore not always possible (Persson & Newman, 2006; Davis et al., 2006).

Most positive participants engaged in one or more strategies to support their health and well-being. Eating healthy food and walking were the most commonly mentioned strategies, followed by other types of exercise or sports. Mental attitude was seen as another important key to health, including ‘having a positive outlook’ and being ‘mentally tough’. Several participants had quit smoking and reduced their alcohol consumption as a way to assist health. Those who had a history of addiction said that abstaining from drugs and alcohol was imperative to their health. Five participants felt that faith, spiritual practice or meditation supported their well-being. Attending AA/NA meetings or counselling was raised by another four. A few also mentioned rest, yoga, massage and avoiding stress as important health strategies, while gardening was mentioned by four men.

Many said that they wanted to do more for their health but felt that their ability to do so was constrained by various factors. These included common life circumstances and competing demands, such as being a sole parent, having a busy job or having significant injuries that prevented exercise. Other factors were directly or indirectly related to having HIV. Persistent fatigue and peripheral

‘I obviously have no control over the fact that I’ve got this virus and that there’s no cure for it. But I am aware that there are certain things that I can do to improve my health if the virus is affecting me, or is going to be affecting me.’

neuropathy made exercise difficult for some. The ability to eat nutritious food, or to eat at all, was challenging for those who had appetite problems. In addition, the cost of healthy food, gym membership, vitamins and alternative therapies was seen as prohibitive by those who subsisted on the disability support pension or who did not have a regular income due to illegal immigrant status.

Despite such constraints, the majority perceived themselves as having a degree of influence over their health. A third felt they had ‘a lot’ of control, while another third felt they had ‘some’ control. One third, however, said that they had ‘little’ or ‘no’ control. This sense of limited control sometimes arose from a feeling that their health was at the mercy of medicine. Gavin, 48, recounted a series of medical mishaps that had adversely affected his health. When asked how much control he felt he had over his health, he replied:

None. I try to do things to keep myself healthy, but I don’t find they seem to work ... I gave up smoking and ... I basically took it back up ... And I’m not gonna give it up [again]. There’s no point. Because I find ... if I don’t have that cigarette, somebody, you know, one of the medications or one of the doctors will do something to make sure I cop it anyhow.

Others argued that they had no control over their health by virtue of their irreversible HIV status. While they could try to manage their health, it would never change the fact that they had HIV. Corey, aged 48, explained: ‘I don’t have any influence over my health to get rid of the problem. Whatever I did it would still be there. So that’s why I say I don’t have any control over that.’ Similarly, for Kevin, 58, his HIV diagnosis, and all that it entailed, had divested him of any sense of being in charge of his health:

I don’t feel I’ve got any control, really. No, I’ve got no control because I’ve got that HIV virus, you know. And I’ve gotta take the drugs. And the side effects and—so to me there’s *no* control ... Your life sort of change as soon as you’re told you have HIV.

While dependence on ART was part of Kevin’s perceived lack of control, others felt that taking treatments enabled them to retain a sense of control over their health. Olivia, 33, said: ‘I think while the treatment for HIV is working, then I feel like I’ve got control.’ While she acknowledged that treatments might not work forever, she also added: ‘But I have control in the sense that the best thing I can do to help that continue the way it has is to always take my treatment twice a day, and not miss doses. So, I guess I do have a lot of control.’ Ellen, 45, spoke of starting treatments as a way to maintain control over her health if affected by HIV in the future:

I obviously have no control over the fact that I’ve got this virus and that there’s no cure for it. But I am aware that there are certain things that I can do to improve my health if the virus is affecting me, or is going to be affecting me. Then there are some things I can do to make that better ... I’ve always had a fairly sort of positive outlook on that in the sense that there’s all these different treatments that I haven’t tried.

This association between treatments and control was consistent with the participants’ strong reliance on medicine as a way to manage HIV in their lives. But some argued that treatments provided only an artificial and therefore unreliable form of control, or else that treatments were only part of the solution. In their view, it was necessary to take charge of one’s physical health by building mental strength. ‘One has gotta be mentally tough because this disease is not only physical,’ Ratu, 43, explained:

[T]he mental side of it plays a whole *big* part of it, yeah. That’s one very big lesson I’ve learnt out of all this. It’s not only, not only medication alone will cure or maybe prolong your life. It’s the mental side of it that is very important. And if you’re only taking medication but your mental side is weak, I don’t think you would be able to last the distance.

A few emphasised the need to take control of their health by not letting the virus take control of their lives. ‘The main thing is I don’t let the virus rule me. I rule the virus.’ Brendan, aged 48, argued. ‘I think if you let the virus dictate your life, you’re fucked.’ Similarly, Lydia, 44, said: ‘I can either let this thing control me or I can control it. And I’ve always been one to, “No, I’m in control.” Like I’m not gonna let this thing ruin my life.’ A similar theme was invoked by several men who spoke of plans to commit suicide if their health failed. The idea of taking their life

before HIV did provided a sense of ultimate control over the virus, as Corey, 48, remarked: 'I will control my life.'

In contrast, others explained that they had developed a sense of control over their health by 'making peace' with the virus, or by learning to understand and co-exist with it. Denise, aged 49, quoted the Latin phrase *ad sanitatem gradus est novisse morbum*, which she translated as: 'To know one's sickness is a step towards health.' She humorously described her relationship with HIV:

To me, HIV is like, because I have had it for such a long time, it's, I'm not saying it's part of my personality, but it's like this little pet monster, you could say. Good boy! You know. Teach it how to do all the right things and it'll behave itself. That's sort of how I look at it ... that it's not just a physical sickness; it's sort of the whole, the whole thing as well, and how it fits in your body. And not to let that little monster get out of control. You've got to keep it happy. You can't get rid of it.

On the whole, most participants felt they had some power to influence their health despite HIV and emphasised the importance of 'doing what you can'. Meagan, 47, summed it up: 'I do a bit of tinkering around the edges ... So, yes, of course I can influence some aspects of my health. I can't influence the big one, but I can certainly make life better to live by influencing the small ones.'

Negative partners and health

Research on the health of negative partners is virtually non-existent. Based on the findings of this study, it is clear that much more work is needed. Compared to the positive participants, the negative partners tended to rate their health less favourably. Yet they reported far fewer physical health problems. But depression and high levels of stress were quite common among the partners and were often seen as an underlying cause of recurring health niggles. Several were or had been on antidepressants. Significantly, about half said their physical and mental well-being was adversely affected by living with HIV, because of issues such as stigma, secrecy, isolation, uncertainty and concerns about their partner's health and the future.

Lowanna, aged 25, spoke of coping with the effects of her positive partner's depression: 'I'm on medication now. I'm on Zoloft because I'm so tense now because of him. He puts me on high string man ... like if you really picked apart at it, it all comes down to his HIV.' Katya, 52, explained that her positive partner's health problems made her feel dejected and isolated:

Emotionally, you know, like stressful and, you know, because like it's a problem; I can't help him. You know, and like it doesn't really make me happy when he's

feeling sick. And you just give up on everything and prefer to stay home ... Like we can go nowhere. Like before when he was feeling a bit better we did go [out] but now we really stop. We can't go. So it's a lot of stress.

Others felt that the stigma and 'code of silence' around HIV in mainstream society impacted on their well-being. Maria, 55, had experienced a number of minor health issues in the past year. She said that having to constantly lie, pretend and conceal her relationship situation at work or in social contexts had a profound effect on her sense of self, eroding her mental and physical health:

I have chronic low-level depression, which I *can't* shift. And I think it's a structural bi-product of inauthenticity ... I can't find that space where I am myself. And I have changed so much in how I relate to people that I, part of me is quite convinced that I am lost. I am psychically lost, which is a very bad state to be in ... My mind and my emotions, which are starving, *starving* from lack of engagement with anybody else in an open way must surely be affecting my body.

For Vikram, 27, intermittent depression was directly linked to HIV, partly because of the sadness he felt about his partner's situation and partly because of not knowing his own HIV status. Two years into his relationship, fears of finding out had prevented him from having an HIV test (see Chapter 4). He felt that his depression affected his physical health and he sometimes worried that his health problems were symptoms of HIV. When asked to describe his current health, he responded:

It's good but not as good as it was two years ago before coming into the relationship. And it's nothing to do with the relationship or with [Ruby]. It's the grief that does it and the depression ... Sometimes not knowing what my status is, or when sometimes HIV comes into the relationship and there are times when we both go into depression. So my health goes down ... I think the immunity level inside me has gone down a lot.

It is noteworthy that the negative partners had some difficulties defining what 'health' meant to them, which might be indicative of the complexity of separating their own health from that of their positive partner. Like several women who were negative partners, Maria, 55, said she had only recently started to attend to her own health, alluding to the way a positive partner's health needs can overshadow those of a negative partner:

When I met [Adam], I had no sense of doing that, on any level, how to take care of myself. On any level. I was hopeless at it ... I couldn't even think that my existence warranted attention ... and so it's taken a long, long time, and a lot of counselling, and many,

many examples of being worn out by the situation, that doing something for my health was fundamental. I'm not terribly good at it. But it's fundamental. So this is what I've done this year.

Most partners thought that their positive partner's health was more important than their own in terms of vulnerability and ongoing management needs. Katya, aged 52, who had many health problems of her own, said: 'Like his health is more important. Like he's deteriorating more quick than me ... I don't have that major problems like he got.' But many couples also emphasised mutual support with regards to health and well-being: 'I think it's pretty two-way; we try to support each other around that stuff' (Olivia, aged 33, positive). Because many couples did not disclose their situation to other people, they tended to be quite isolated and reliant on each other for support. As Katya's partner Gavin, 48, said: 'Oh, we have to. Nobody else will.'

Several partners said that their positive partner was involved in their health by encouraging a healthy lifestyle or by providing practical and emotional support. Vikram, 27, said of his partner: 'She's always supported me in whatever way.' Alice, 23, described her partner in the same way and also credited him with helping her to get off drugs:

He's trying to encourage me to see a counsellor and stuff ... He's heaps supportive of me in everything I do. And he's always trying to steer me down the right direction in case I fall off. But, yeah, he's, he's fantastic ... He's the reason, I have to say, that I got off drugs ... I think without him I don't know where I'd be right now ... Maybe I would have stopped; maybe I wouldn't have. Maybe I'd be dead. I don't know. But yeah, he's definitely changed my life for the better, heaps.

Yet, the impact of HIV on the negative partners' well-being was often a fraught and delicate issue not easily addressed. Some negative partners found it difficult to communicate

'You know, like the extent to which he will work to look after me is indicative of how aware he is of what it must be like for me. And feels responsible for it. So I don't want to make him feel more responsible for it ... I mean, you know, he does all he can do and he's not responsible for HIV; he's just got it.'

their experiences because of the burden of responsibility it evoked in their partner. Vikram, 27, stated: 'When she sees me down emotionally or [when I'm] thinking [that] maybe I have [HIV], it does affect on her. But she, it reminds her of HIV first of all and then it looks to her it's all happening because of her. It gives her a guilt feeling.' Some saw it as an unresolvable issue and wanted to protect their partner by not raising it. Maria, 55, who described her depression as a bi-product of HIV stigma and silence, elaborated:

He looks after me like I've never been looked after by anybody. And my well-being and my safety and my happiness is more important to him than anything else in the world ... But I can't talk to him about ... what's going on for me because it makes it hard for him. And he is already trying to make a difference anyway. You know, like the extent to which he will work to look after me is indicative of how aware he is of what it must be like for me. And feels responsible for it. So I don't want to make him feel *more* responsible for it ... I mean, you know, he does all he can do and he's not responsible for HIV; he's just got it.

This dilemma was similarly apparent among positive partners. Many found it hard to address the issue, both in the interview situation and with their partner. Some expressed uncertainty about their negative partner's feelings. Difficulties communicating about the health impact of HIV on negative partners might explain why some felt that their positive partners were not particularly sensitive or responsive to their experiences of 'living with HIV'. However, it may also be the case that a general lack of attention to and validation of negative partners' experiences in the HIV sector compounded such communication difficulties.

In contrast, many negative partners spoke positively about their positive partner's health. With the exception of two women whose husbands had very poor health due to late diagnosis, most negative partners described their partners' health as 'very good' and often emphasised their resilience against HIV. Alice, aged 23, noted her partner's robustness after 12 years with HIV: 'Like I think he's healthier than me [laughs] ... Like he's got more endurance than me, heaps more energy ... He's been through a hell of a lot and, like, I don't think anything can break him.' Lowanna, 25, marvelled at how healthy her partner was, so healthy in fact it seemed he did not actually have HIV:

He's just *amazing* the way he just doesn't show any signs of having any sickness whatsoever. *Whatsoever* ... I just don't think he's got [HIV] anymore. I swear to God I don't think he's got it ... I just get this feeling all the time of he just doesn't have it. And I just put that in my mind and I think as long as I put that in my mind it's gonna stay as it is.

As hinted in this quote, there was a certain tension between this emphasis on good health and concerns about what would happen in the future. Descriptions of their positive partner's health were often suffused with hope rather than certitude. Vikram, 27, said: 'At the moment I would say she's in good health. Very good health. And I hope and pray to God that she keeps like this forever.' When asked if he ever worried about his partner's health, Gabriel, 44, responded with a mix of fatalism and optimism:

Yeah, yeah, I'll admit to that ... And it's always gonna be there because it's a fact of the virus and how it is. It can happen. As long as, no, as long as she maintains her medication and she looks after herself, she'll be fine. But yeah, that's always a worry there ... And she's had it for about eight years. As long as she looks after herself she should be, she'll be fine. But it, this will happen. You know, definitely it will happen, one day.

As noted in Chapter 1, most negative partners were not involved in medical decision-making. But they were often involved in their positive partner's health in other ways, most commonly by accompanying them to their HIV clinic or doctor, by encouraging them to live a healthy lifestyle and by being a source of emotional support. Some female partners also said that they tried to support their partner's health by cooking nutritious food or by keeping the home clean 'just in case he gets the flu or something that can make him sick' (Alice, aged 23). Claire, 40, said:

When I found out about this my attitude was, 'OK, what are we gonna do about it? Let's make sure it doesn't kill you and the only thing I can do is make sure you're eating properly, that you're resting, that ... you're not overworked, stressed and all the rest of it. I can't do anything with drugs; that's the doctor's job, but I can help with the lifestyle.'

As is consistent with conventional gender patterns, female partners were often closely involved in their positive partner's health. But other dynamics were also at play. Phoebe, aged 36, was immersed in every aspect of her husband's care after his diagnosis with an AIDS-defining illness 18 months ago. Still reeling from the shock, she explained that 'taking control' was her way of coping with the situation. For Maria, 55, whose partner was near death when combination therapy arrived, creating a life that supported his daily dosing regime was of outmost importance:

I do everything I can to keep him stable and comfortable and resourced, strong to do that. Because our lives and our happiness depends upon his ability to do that ... This tip of our life is sitting on this mass of chemicals, and his ability to take them in, physically process them and survive because of them.

Positive partners often emphasised the value of their partner's involvement in their health, especially if their family was unsupportive or unaware of their HIV status. Yet, there were some tensions: positive partners were not always sure about their partner's level of interest, while negative partners expressed uncertainty about their partner's needs. Silence was particularly difficult to interpret for both partners and tended to produce doubts or friction. Zoe, 26, felt that her partner was more concerned about his own health:

No, he doesn't ask me anything to do with my HIV, or like how's my health going, or anything ... I mentioned to him the other day that I should go to the clinic, then he's more worried about checking himself. He's not worried about me or how I am ... I'd like him to ask me, you know, like, you know, it shows that he cares. But otherwise if he doesn't ask, or he's more worried about himself, yeah, it's like he doesn't care.

A negative partner's silence made it difficult for some positive partners to gauge their partner's knowledge about HIV. They felt responsible for informing their partner about HIV-related health issues, but were unsure whether they did so unnecessarily. Olivia, 33, said that her husband was very supportive, but added:

I think it would be good if he asked more questions ... sometimes I wonder if he, you know, has a really good understanding of stuff, and I *want* him to be really well informed ... I don't know whether he already knows that stuff or not.

Conversely, some negative partners spoke of trying to negotiate a fine line between wanting to be supportive and wanting to not unduly draw attention to HIV in case it

'Like I probably should get a bit more involved. It's just—I don't know how to bring up some things. Like I don't know when the moment's right. I don't want to make him feel worse or anything ... I worry about him a lot but, yeah, we, it doesn't really, it's not something we talk about a lot.'

would upset their partner. Lowanna, 25, explained that her partner was much happier when he did not think about HIV, so she avoided doing anything that would remind him. Similarly, Alice, 23, said:

Like I probably should get a bit more involved. It's just—I don't know how to bring up some things. Like I don't know when the moment's right. I don't want to make him feel worse or anything ... I worry about him a lot but, yeah, we, it doesn't really, it's not something we talk about a lot.

Some positive partners said they did not want to burden or inconvenience their partner, for example by asking them to come along to their clinic, as Carlos, aged 37, said: 'I like to spare her sitting in a waiting room for an hour.' Conversely, some negative partners felt that their positive partner did not want to involve them in their health issues for the wrong reasons. Gabriel, 44, said:

See, [Lydia] has this thing about not wanting to burden anyone, even me ... She just tries to struggle on alone

with it. I said, "You know, you've got to talk to me about this stuff" ... She thinks it doesn't affect us, but it does.

It is evident from the interviews that HIV has the capacity to affect the health and well-being of both positive *and* negative partners. Yet this is rarely acknowledged in the sector and is therefore likely to impact on communication in couples. As these stories suggest, involvement and communication around health were both important sources of support and potential sources of tension and misunderstanding. In addition, lack of contact with couples in a similar situation meant that most partners had few opportunities to discuss and learn from the experiences of others, which tended to deepen feelings of isolation and silence. This highlights the need for more resources and support strategies specifically tailored at *both* partners in serodiscordant relationships.

3 Health services

As discussed in Chapter 1, there was a tendency to invest heavily in HIV medicine. This tendency is embedded in the cultural context of HIV and heterosexuality in

Faced with the stigma and silence surrounding HIV in heterosexual society, medicine provided a kind of refuge and tangible solution to managing and compartmentalising HIV in their lives. Their HIV doctor or clinic was often their primary or only contact with anything related to HIV.

Australia. Because of their limited contact with the HIV community or with peers, the participants had limited exposure to diverse discourses or ways of living with HIV. Faced with the stigma and silence surrounding HIV in heterosexual society, medicine provided a kind of refuge and tangible solution to managing and compartmentalising HIV in their lives. Their HIV doctor or clinic was often their primary or only contact with anything related to HIV. Consequently, this relationship was of some importance to the participants and therefore also of importance to understanding how they experienced and negotiated HIV. This chapter explores their interactions with HIV health services, as well as their rather different experiences of the general health sector.

Contact with HIV health services

The participants had been diagnosed with HIV in a range of health settings and circumstances, with some noteworthy patterns. None of the men had been diagnosed at a sexual health clinic and only one man had been diagnosed at an inner-city general practice with a high case load of HIV patients. Half the men had been diagnosed by their regular/local GP (all non-S100-prescribers), while a quarter had been diagnosed when in hospital with severe illness. Two men had been diagnosed in a drug and alcohol rehab centre and another man through

routine testing in the army. Women were more likely to have been diagnosed at a sexual health clinic. Two women had been diagnosed by their regular GP, while three women had been diagnosed in hospital and one woman at a Family Planning clinic.

For their ongoing HIV health needs, more than half the men attended HIV clinics at major Sydney hospitals, while three attended suburban or regional sexual health clinics and another two a metropolitan sexual health clinic specialising in HIV. Only one man went to an inner-city general practice with a high HIV case load and another man attended a private hospital. Over half the women attended sexual health clinics in urban, suburban and regional areas. Three women went to HIV clinics in hospitals, and one saw an S100-prescribing GP. None of the women attended inner-city general practices with high HIV case loads.

Over a quarter were still seeing the same HIV doctor at the clinic or hospital where they were diagnosed, while nearly half were still seeing the HIV doctor or clinic they came in contact with shortly after diagnosis. Others had been seeing their HIV doctor or clinic for many years. Most said they had chosen their current HIV health service because they were diagnosed there, or because they were referred there shortly after diagnosis. Only a few mentioned proximity as a deciding factor.

Common reasons for staying with their current HIV health service included: trusting and liking their doctor; being known by clinical staff; feeling welcome, accepted and safe there; and that the service had their medical records and knew their history. Several participants stayed with their doctor or clinic even though other HIV health services were available closer to home, and some travelled considerable distances across Sydney or from a regional area to see their HIV doctor or clinic. Less than a third had changed their doctor or clinic in the past. Reasons for this included relocating within Australia, Sydney or from overseas, losing faith in their doctor or feeling out of place attending a clinic that focused on gay patients.

The majority of participants visited their HIV doctor or clinic every three months for regular blood tests, a health check-up and renewal of medical scripts, with almost a third also seeing a psychologist or social worker as part of their clinical visit. Five participants attended their doctor or clinic on a monthly or bi-monthly basis because of health complications, or because they needed closer monitoring due to change of treatments or drug failure. Only one man, who had been positive for 15 years and had never been on treatment, did not have consistent contact with HIV health services: 'I've never really gone regularly. I've only turned up when I felt the need to.' At the time of the interview, he had not seen an HIV doctor for over two years, citing the demands of being a sole parent and having fallen out with his doctor.

The most commonly raised issue associated with attending an HIV doctor or clinic included length of travel or transport problems. Nearly all participants with a history of injecting drug use commented on the difficulties of giving blood due to scarred veins and, for Angus, 53, this was a deterrent to regular HIV health care. Some wanted to be able to draw their own blood instead of having a nurse do it, or give blood less frequently, but felt obliged to follow protocol: 'Basically I have trouble getting my medication if I don't have my blood test every three months. It's almost like I'm held over a barrel, I feel' (Rowan, aged 53). Others found it onerous having to get a new script for their ART every month, especially if they had to travel a long way, while others mentioned the difficulties of making up excuses for taking time off work to attend day-time-only appointments. Concerns about being seen entering a clinic by somebody from their cultural community were also raised, including by Fatima, 32, who said that 'everyone knows it is a place for people who have something wrong with them'.

The majority attended their clinical appointments by themselves, unaccompanied by partners, family or friends. Some said they preferred it that way because their health was a private matter, or else they did not see it as an issue because they were so used to it. Others had no one who could come with them because they lived an isolated life or had not disclosed their HIV status to anyone. Several participants, men in particular, spoke of their loneliness with HIV, including Antonio, 71, who had attended his appointments on his own since he was diagnosed in 1984:

I've always done it alone. No one ever help. How I done it all the time, all on my own, I don't know ... Something you get used to. You don't need a chaperone now. At the beginning you do. Because it's something new ... I always wanted someone to back me up, but I have never found my family [supportive]. None of them.

About a fifth were regularly accompanied by their partners or by family members, usually small children, when attending their HIV doctor or clinic, while a quarter were occasionally accompanied by their partners or had been in the past. Many felt that having their partner come along was not only emotionally supportive but also important. Some felt that their partner functioned as an extra pair of ears and eyes to pick up information and ask questions, as Gavin, 48, put it: 'I do prefer her to come with me in case I forget something. Or miss something.' Others emphasised the educational opportunity for their partner, for example Olivia, aged 33: 'I think it's important to me that he knows what's going on and that he has a good understanding of it. That he's well informed.' They also pointed to the importance of partners receiving impartial professional information untangled from relationship dynamics.

A number of participants, mainly men, would also see various specialists on a regular basis, most commonly cardiologists and neurologists, for a range of HIV-related health problems, particularly those who had been late presenters or who had been positive for a long time. All women were aware of the recommendation for positive women to have regular pap smears. Except for one woman who found the procedure too painful, all women had a pap smear either yearly or six-monthly.

The clinical relationship

The doctor–patient relationship is central to HIV care. The benefits of a good doctor–patient relationship are well documented. For example, it has been argued that the quality of this relationship is critical to the experience of treatment (Wheeler, 2005), to adherence to treatment (Schneider et al., 2004) and to HIV health and health care more generally (McCoy, 2005). Trust, understanding and open communication have been identified as important features of the clinical relationship (Wheeler, 2005; Johnston, 2002). Others emphasise that a sense of being respected is important to patients' feeling safe and comfortable to divulge information to their doctor (McCoy, 2005; Kremer & Ironson, 2006). In this study the clinical relationship had added importance and meanings.

At first glance the participants described a fairly traditional doctor–patient relationship in which HIV expertise was firmly located in their doctor (see Chapter 1). But a closer reading suggests that their clinical relationship was also different from a traditional model in some important ways. Because of the stigma and silence around HIV in heterosexual society, most participants had compartmentalised their HIV-positivity to the clinical

relationship. Given that their HIV doctor or clinic was often their primary or only contact with the broader HIV sector, and given that it was often one of few contexts in which they had actually disclosed their HIV status, the participants tended to place considerable importance in this relationship. It provided a unique space in which their HIV status was acknowledged and their humanity validated.

All but one participant expressed significant satisfaction with their HIV health care provider and many spoke very highly and affectionately of their doctor. When asked what they most valued in their relationship with their HIV doctor, their answers centred on a sense of common humanity, rather than on authority and expertise. They referred to qualities such as being friendly, warm, caring, supportive and approachable. The same qualities were valued in allied health workers, such as clinical nurse consultants, dieticians and social workers. In any clinical interactions, being made to feel welcome, safe and accepted was seen as highly important and several used words such as 'home' and 'family' to describe their HIV clinic. Ratu, aged 43, elaborated:

Oh, over the moon, mate ... It's like a little family, you know. They're like my family sort of thing, you know. Yeah, they're very good ... the way they speak to people and—because it's, well they go out of their way to make people feel welcome and feel at home ... They don't just like come and throw you the medication and say, 'See you later. Take it and when you're finished, come back,' or something.

HIV is not only stigmatised in heterosexual society; there is also significant curiosity and widespread assumptions about positive heterosexuals and how they became infected. Against this background it is not surprising that many participants placed great value on being treated

'They've just been worth their weight in gold to me ... just the confidence they've instilled in me ... It gives me so much more peace of mind and helps me deal with this virus. So, yeah, I'm over the moon.'

with respect and dignity by HIV doctors and other clinical staff. Antonio, 71, praised his HIV specialist because 'she treats her patients all equal ... she treats you as a human being'. Several explained that it was this kind of non-judgmental care that had helped them to come to terms with their HIV status. Victor, 34, said: 'They've just been worth their weight in gold to me ... just the confidence they've instilled in me ... It gives me so much more peace

of mind and helps me deal with this virus. So, yeah, I'm over the moon.' Men in particular tended to emphasise the importance of their clinical relationship, perhaps because they often had less access to other sources of support. Carlos, 37, said:

I get that sense of warmth and care there. So, they're very special people. I hold them very dear, very close to my heart. As much as my family. Because if it wasn't for them I wouldn't be here. I wouldn't have my health the way that I have ... I feel very secure, because of the help and the care that I have. So that's improved my quality of life very much ... [T]he most important thing that I've always had is my doctor, there at [the clinic]. She's always been there for me, encouraging me to live a quality life.

Given the isolation experienced by many positive heterosexuals, and the related emphasis on medicine and everyday normalcy as a way to manage HIV, the clinical relationship provided a safe and segregated space in which they could engage with being HIV-positive. 'I pretend that I don't have nothing. I'm just living normal,' explained Mahmoud, aged 32. 'Only when I go to the doctor's for that appointment every three months, that's when I do everything. And after that I forget about HIV. I walk out. I haven't got HIV. That's it.' Being able to rely on this relationship whenever HIV intruded into their lives was highly appreciated, as Lydia, aged 44, explained:

If I'm having a bad day I can just walk in there. I can ring someone up and bang! I've got support like left, right and centre. I know all the nurses there. Everyone is just so supportive there, it's brilliant. You know, I wouldn't look at going anywhere else ... because I've been going for seven years they've kind of got to know me as a person now. And yeah, you know, if I do have a really bad day, they are concerned and that.

Because of the importance of the clinical relationship as one of few social spaces in which their HIV-positivity was attended to and cared for, any dissatisfaction commonly centred on interpersonal dynamics and accessibility. Several participants, who incidentally all went to the same hospital HIV clinic, commented on the clinic's reception staff:

[T]hey're just like not very empathetic or sort of quite rude. Like any old receptionist can be. But, you know, I have this expectation that in a place like that when you're dealing with people who, you know, maybe have this disease, that you should be a little bit gentle and so on.

(Ellen, aged 45)

Others said that they would like more time with their HIV doctor, or would prefer to see him or her more often. Being seen by different doctors in the clinic, rather than by the

specialist, was also raised as a concern, partly because they had to contend with ‘too many different opinions’ and partly because it made them feel de-prioritised. Three men had some doubts about whether their HIV doctors made decisions in their best interest or whether they were being used as experimental case studies, which had caused one man to ‘lose faith’ in his long-term doctor and stop going to his clinic. Those who attended regional sexual health clinics also expressed some reservations about the expertise in HIV among clinical staff.

On the whole, however, most participants were extremely complimentary about their HIV doctor or clinic. The strength and supportiveness of the relationship between positive heterosexuals and their HIV doctors is heartening. But it also makes positive heterosexuals highly reliant on and therefore vulnerable to any changes in primary care. In addition, outside of this clinical model, the participants’ interactions with non-HIV health services and health workers tended to be more complicated, as discussed in the next section.

GPs and other health workers

For any health issues outside specialised HIV care, most participants needed to attend general practitioners and other health professionals. Only two saw an S100-prescribing GP for both HIV-specific and general health care.⁸ A majority of participants had a regular non-HIV GP whom they visited for their general health care, and several still saw their diagnosing GP. Among those who did not have a regular GP, some would see different GPs at their local medical centre, while some men said they did not seek much health care and others were trying to find a suitable GP. The task of establishing a satisfactory relationship with a GP was not regarded as easy. Carlos, aged 37, commented:

I’d like to find a doctor that I could confide in. But it’s very difficult because my [HIV] doctor, you know, has set a very high standard for the other doctors. So it’s very hard for me.

Several qualities were considered important in a GP and these differed somewhat from the qualities valued in an HIV doctor. There was more emphasis on attitude and knowledge in relation to GPs. A good GP was described as someone who was non-judgmental, accepting, open

and interested, or as Grace, 66, put it, had ‘no inhibitions about the HIV’. Basic medical knowledge of HIV was seen as another desirable but rare quality in a GP, with many participants saying that GPs ‘know nothing about it’ and tended to ‘blame everything on HIV’. As Gavin, 48, joked: ‘Everything’s HIV-related. “You broke your toe? Oh that must be HIV-related.”’ Those who had found a GP with at least some of these qualities were often keen to maintain this relationship. Dean, aged 49, said:

I’ve chased him around through a few medical centres ... I don’t like disclosing to a new doctor every time I go to the doctor’s. [Doctors] have to know this. You know, he’s the doctor. So that’s why I try and chase my doctor around. And I really need to inform him about how hard it was to keep track of him last time he moved. And get him to tell me when he’s going to move. But I’ve had him since before diagnosis.

Disclosure of HIV status to GPs was a vexed issue for most, partly due to privacy concerns and partly due to past interactions with GPs and other health workers. Many participants felt there was widespread ignorance about HIV in the general health sector. All but three said that they had experienced negative or discriminatory treatment by a GP or other health workers. Gavin, 48, said: ‘When I got told I had HIV, I got told that no health care professional was supposed to treat you *any* different. That’s a load of rubbish. That is a *total* load of rubbish.’ Similarly, Lydia, 44, observed:

Sometimes I find if you *do* disclose ... it’s amazing, even in the medical profession, how the change happens. It’s just, you know, it just blows me away. I mean these are doctors for God’s sake ... So, yeah, there’s still a lot of ignorance and fear. But I can understand the fear. I can understand that kind of fear. But I would have thought that doctors might have known more.

This theme would come up in interview after interview. Several participants described what they perceived as ‘discriminatory’, ‘uninformed’ and ‘unprofessional’ treatment by GPs or in hospitals, including breaches of confidentiality, being treated differently from other patients or being told they had to be put last on the surgery list to protect other patients, as recently happened to Sabrina, aged 46:

I said, ‘What do you mean?’ I said, ‘I’m the one with the low immune system’... I want to know why in 2006 this has happened. Why are they, you know, why are they treating me like a leper when I should be the one that’s protected?

Others described ‘frosty’, ‘judgmental’ or ‘moralistic’ attitudes on the part of GPs and health workers. Victor, 34, said: ‘I’ve seen a few, you know, that definitely haven’t really got a good attitude ... Just, yeah, sort of the way they

8 Compare this with the HIV Futures study (Grierson et al., 2006, p. xi), in which the majority of participants are positive gay men. For HIV-specific treatment, 43.2% saw an HIV GP/S100-prescriber and 32.4% saw an HIV specialist/physician. For general health care treatment, 46.7% of people living with HIV/AIDS saw an HIV GP/S100-prescriber and 25.1% saw a non-HIV GP. For 37.7% of respondents, these were different doctors.

look at me. The standoffish sort of attitude. I definitely know there's something there inside their mind when they see the HIV bit.' Others mentioned being treated with suspicion or curiosity by GPs or hospital staff, or having assumptions made about how they became infected. Antonio, 71, who had a long history of medical encounters with various specialists, objected to 'nosy questions':

They want to ask you how long you've had it, how did you get it, have you been with men or have you been with prostitutes. It's irrelevant. I've got it, I've got it. It's one way or the other. I don't have to be asked those questions. So when I go to a doctor I want him to treat me, from what the referral my GP gave him. I don't feel like to have to be interrogated.

Despite such experiences, the majority tended to disclose their HIV status to GPs and other health workers. Some thought they were required to do so. When asked if he disclosed, Mahmoud, aged 32, replied: 'Don't I have to tell them? Well, I just thought you have to tell the doctors. I don't know. I just thought, because they ask you. They ask you have you got any medical problem.' Others felt that it was important to disclose. As Carlos, 37, put it: 'It's in *my* best interest ... when I go to see the doctor I have to tell them everything that's wrong with me if I want to have an accurate assessment and avoid any problems.' They saw their health needs as being different because of their HIV status, as Victor, 34, explained:

I do believe [disclosing] helps *me* ... As a positive person, you know, I'm not the same as everyone else that's, that's negative. Yeah, I just think it holds me in good stead for an overall diagnosis or treatment of a problem, whatever it may be.

However, a few participants disagreed with this view and argued that if they sought general health care, they should not be treated differently from any other patient and should therefore not have to disclose. Antonio, 71, explained: 'I think a doctor should treat everybody the same, whether you are HIV or not. They should wear gloves and they have precautions. And I don't have to tell them what I have.' For the same reason, Ellen, 45, did not disclose to GPs. She recently sought treatment for pneumonia: 'I just went to the local GP on the next corner because whilst it may have been sort of HIV-related, I mean it's not something that they would need to know, or that would be any different. The treatment would be the same.'

While nearly all participants said they had encountered negative or judgmental treatment by GPs or health workers, those who had been positive for a long time were also keen to point out that things had changed for the better. Meagan, aged 47, noted the recent clinical change from using rubber gloves with some patients to hand-

washing after each patient: 'I'm really pleased at those changes. Pleased at that attitude, that everybody could have anything. It's about time ... I'm delighted with that. It makes me feel a little less like a leper.' However, the findings here also suggest that this process is incomplete and that more or better education about HIV among health workers is still needed.

Negative partners and services

Among negative partners, interactions with HIV health services ranged from frequent contact with doctors and hospitals because of their partner's poor health, to minimal contact because they did not attend their partner's clinical appointments. Those who did have some contact were mostly complimentary and felt that they were treated well as a negative partner. Lowanna, aged 25, said of her partner's HIV clinic:

Oh my God, it's like a little family. When you're in there, you get cups of tea, bikkies. And they always talk to the kids. They love the kids. They're so lovely ... I mean they'd do anything for me.

Points of tension usually centred on not feeling adequately supported as a carer. Phoebe, 36, said: 'Yeah, there's times when you think, you know, you do feel quite alone ... It is a burden because it's just *so* full on.' Others spoke of not feeling validated as a negative partner. Claire, 40, said of her partner's HIV doctor:

In the beginning he rarely even acknowledged that I was there. I felt that was a bit rude. Because, yes, [my partner's] illness affects, does have a direct impact on me, and I could get it. And, while it's not easy to catch, I'm more likely to get it than anybody else off him. So I felt a little bit like maybe the doctor was sort of just seeing how, if I was gonna be in there for the long haul. I don't know.

Most of the negative partners' involvement with HIV health services revolved around the health needs of their positive partner, rather than their own, with only a few having their HIV tests done at their partner's HIV clinic (see next chapter). For their own health care, negative partners went to GPs. As noted in the previous chapter, half the negative partners said their well-being was adversely affected by living with HIV. Yet their ability to address this aspect of their health with GPs was complicated by problems similar to those faced by the positive participants in the general health care sector.

Several negative partners had encountered uninformed, judgmental or alarmist attitudes among GPs when seeking an HIV test or when disclosing their situation. Some

had even been warned by GPs not to have sex with their positive partners and urged to immediately end their relationships. Vikram, 27, went to a GP when he first met his partner: 'I thought I would get some help and support. But it went the other way. He asked me to like, [he] scared me and said just as soon as I can just get over the

'I go to the doctor quite frequently because I just go—I just get worried all the time ... I just go to a local doctor near home. Yeah, and I told him straight away, and he's been really cool about it ... Even the lady at pathology, like where I go to, I know her well enough now and she understands what I'm living with ... And I trust her.'

relationship and try to save my life.' Some spoke of being interrogated or having assumptions made about them when they asked for an HIV test. Gabriel, 44, said: 'Yeah, I've had doctors ask me, "Are you gay?" And I say [laughs], "Well why? Are you?"' Conversely, others encountered a lack of understanding of the issues still facing people living with HIV. Maria, 55, had changed GPs several times, frustrated with their lack of experience with HIV:

[T]hey weren't on top of the issues, the isolation issues. They actually wouldn't acknowledge. I would get into a struggle with them around isolation and depression because they would say, 'But it can't be true in 2006 that people are isolated because of HIV.' So I gave up. And I was really angry with them as practitioners that they would negate, because you can't go anywhere then in the discussion.

For these reasons, negative partners were reluctant to disclose to GPs. However, as was the case with some positive participants, some negative partners felt that HIV was irrelevant when seeking general health care and therefore saw no reason to disclose. Claire, aged 40, was happy with her regular GP but had not disclosed to him because she did not think there was a need for him to know: 'I'm negative, so until that changes I'm just the same as anybody else.' Others, however, felt it was important to disclose because they saw their health issues as directly related to living with HIV, or they simply needed to confide in someone. Phoebe, aged 36, said:

I go to the doctor quite frequently because I just go—I just get worried all the time ... I just go to a local doctor

near home. Yeah, and I told him straight away, and he's been really cool about it ... Even the lady at pathology, like where I go to, I know her well enough now and she understands what I'm living with ... And I trust her.

Few negative partners accessed support specifically for themselves. They generally had little contact with any HIV service. When they did, it was usually to organise financial or practical assistance for their positive partner. Only two had been to counselling through HIV-related services, such as Ankali, while another woman had sought counselling from outside the HIV sector. A few had attended the Western Suburbs Haven or Pozhet, but mostly on a one-off or sporadic basis.⁹

Reasons for not making use of services were diverse. Some said there was little specific support for serodiscordant couples and, particularly, for negative partners. Others were too busy or felt no need. Some explained that HIV did not have an impact on their lives and they therefore saw little reason to seek support. Lowanna, 25, stated: 'It's not like I'm his carer or have to care for him and have to take him to doctors' appointments or nothing ... So we just live our lives normal. Like my mum and dad live their lives.' But there was also a sense in some interviews that seeking support would disrupt this investment in normalcy by signalling that HIV was somehow a problem. The partner of Alice, aged 23, had encouraged her to seek counselling but she was reluctant:

Like I don't *think* I have a problem ... I've seen a counsellor before about living with a partner with HIV, only once. But she told me I don't seem like I have any problems or any worries, or like I need to worry about anything ... I don't really think that I need counselling for living with [Carlos] with HIV. No, it doesn't; I really don't think it affects me in any way.

Along these lines, some said that they would attend Pozhet events or other services for the sake of their positive partner, rather than their own. Gabriel, aged 44: 'Personally it wouldn't really hold any interest for me, but I mean if [Lydia] wanted to go, I'd go along with her. Other than that, there'd be no reason why I'd go.' But a few partners disagreed. Vikram, 27, emphasised the importance of peer support, while also noting some of the barriers:

[W]e've tried to go so we can meet other couples, other people in a similar situation. It's a pity like, in Pozhet, they try to organise for a lot more people but a lot of people try to keep it private and they don't come to the

9 Access to HIV support services among positive participants was discussed at length in the Straightpoz report, Volume 1.

support groups ... And, or they don't want to talk about it, which is a bit of a shame. Like they should be happy to meet other people and try to help each other out so that others can get help as well ... So that's why I always ask [Ruby] to go there ... It does provide a lot of help.

As Vikram's quote highlights, concern around privacy and confidentiality was another reason for some partners not making use of services. Phoebe, 36, said that what she most needed was support and 'education', having found out only 18 months ago that her husband of many years was HIV-positive. Yet she was reluctant to seek available support for heterosexuals or for families with HIV:

I'd be scared but, of whom I might meet and how close they are to home, and my life. You know? ... And because, maybe, you know, they've told, chosen to tell people. They mightn't understand how much I've chosen *not* to. You know? So, yeah, I don't think I would go to it.

The findings here suggest that access to health and support services for negative partners is shaped by differing needs, as well as by relationship dynamics and the availability of appropriate services. They also suggest that negative partners continue to be a largely invisible group of people 'living with HIV' and that efforts by the health sector to engage this group and meet their differing needs must continue.

4 HIV and sex

HIV can have a profound impact on people's sense of themselves as sexual beings and on their confidence and capacity to negotiate new intimate relationships. As Brendan, aged 48, put it: '[HIV] puts a fucking hell of a clamp on your love and your sex life, I'll tell you.' The difficulties of disclosing to a sexual partner, together with fears of rejection and transmission constitute some of the barriers to sex. This was explored in the Straightpoz report, Volume 1.

The first phase of the study also found that consensual unprotected sex was

... the second phase of the Straightpoz study aimed to gain further insights into serodiscordant sexuality through a deeper exploration of the participants' understandings of 'safe sex', their sexual strategies and negotiations, and the meanings of HIV-negativity and HIV testing.

common among serodiscordant couples and that regular HIV testing was not the norm among negative partners. Other research also suggests that a significant proportion (between 20% and 60%) of positive heterosexual men and women practise unprotected sex with their negative partner, with no apparent gender differences (van der Straten et al., 1998; Stevens & Galvao, 2007; Milam et al., 2006; Skurnick et al., 1998; Aidala et al., 2006; Buchacz et al., 2001). Yet there is little research on the dynamics of sexual practices among serodiscordant couples. Against this background, the second phase of the Straightpoz study aimed to gain further insights into serodiscordant sexuality through a deeper exploration of the participants' understandings of 'safe sex', their sexual strategies and negotiations, and the meanings of HIV-negativity and HIV testing.

To date, 19 serodiscordant couples in all are represented in the Straightpoz study, with either one or both partners participating in the study (see Introduction). It should be noted that the

term 'serodiscordant relationships' usually denotes known serodiscordance, that is, the positive partner has disclosed his or her HIV status to the negative partner. Among the 19 serodiscordant relationships included here, all were known, with the exception of one new couple in which the positive woman had not yet disclosed her status and did not practise penetrative sex. Among these couples, 14 were sexually active at the time of the interviews, including six of 11 couples in which the man was positive, and all eight couples in which the woman was positive. Nearly all practised penetrative sex and half practised unprotected penetrative sex. While this discussion draws on findings from both phases of the study, it focuses predominantly on interviews from the second phase. In this phase, five positive men, five positive women and eight negative partners were in serodiscordant relationships.¹⁰ A majority of the remaining 16 positive participants had been sexually active at some point since their diagnosis, including with negative partners, in both long and brief relationships as well as with casual partners of unknown HIV status, with five men occasionally or regularly having had sex with commercial sex workers.

Understandings of safer sex

Many participants said that they were aware of safe-sex messages but did not practise safe sex prior to their diagnosis or prior to meeting their positive partner. Their explanations for this tended to be gendered and indicative of the marginality of HIV in heterosexual society. A common theme among the positive men was that they 'didn't give it much thought' at the time. Invoking conventional discourses of masculinity, they described themselves as 'young' and 'reckless' or as 'having a good time' and feeling 'invincible' or 'bullet-proof'. Tobias, 53, said: 'I knew you could

¹⁰ One negative female partner not included here had separated from her positive partner with whom she had been sexually active throughout their 12-year relationship.

catch STIs¹¹ but that was something that happened to other people, really.’ Some men thought they were safe on the basis of a perceived ability to identify ‘safe’ and ‘clean’ female sexual partners (see Waldby et al., 1993a).

Others had not considered safe sex to be a personal concern at the time because they had been in an assumed monogamous relationship. This theme was more common among the women, both positive and negative. They explained that they had practised unprotected sex with their partner or husband, believing the relationship to be safe, which for some turned out not to be the case. Several women also mentioned the difficulties of adhering to safe sex because, as Sabrina, 46, put it, ‘you know what men are like’ (see Hollway, 1984). Others described how their understanding of safe sex had mainly centred on avoiding pregnancy. This theme was common among older participants and those who were diagnosed early in the epidemic but was not exclusive to them. Several themes converge in this quote by Zoe, aged 26, who was diagnosed in 1998:

OK, before I tested positive, the only thing I was worried about is getting pregnant. And I was on the Pill ... I learnt about, you know, safe sex and condoms and stuff at school. But I don’t know ... the guy that gave [HIV] to me never ever used, wouldn’t use condoms ... You think that nothing will happen to you. You don’t even think. I never thought that I would get HIV for it. You know? It just didn’t come to mind.

For most participants, understandings of safe sex shifted with their HIV diagnosis or upon meeting their positive partner. A desire to prevent transmission of HIV was the norm among the participants, irrespective of their HIV status. Nearly all now interpreted safe sex to mean the use of protective barriers to prevent exchange of bodily fluids, with an emphasis on condoms with any penetrative sex. But this textbook definition did not necessarily carry the same meanings and implications for all on a personal level. Yet regardless of their own sexual practice, almost everyone expressed unequivocal views on condoms, including Angus, 53, who had practised both protected and unprotected sex with negative partners who were aware of his HIV status: ‘That’s all there is to it in my eyes. There shouldn’t be any “do this or that” ... Penetration occurs; stick the condom on. That’s it.’ Maria, 55, who always had protected sex with her positive partner, said: ‘There is no alternative to safe sex. You *have* to have a condom. That’s it.’ Victor, 34, who had had protected sex with casual partners and sex workers, stated:

There’s only one thing and it’s called a condom. And it’s all I really understand. I don’t believe there’s any more to safe sex than that. That’s the only understanding I

have. I really wouldn’t want to be prone to listening to anything else, anyone else’s opinion.

Others similarly emphasised condoms, but would add other elements to this interpretation of safe sex, including lubrication, checking hands, mouths and genitals for cuts, being ‘clean’ and ‘knowing your partner’. Several positive participants also mentioned disclosure as a key aspect of safe sex. But others strongly rejected the obligation to disclose to casual partners as unreasonable and as irrelevant to sexual safety if they used condoms. In addition to the use of condoms, some described a broader repertoire of safe sex, including foreplay, the use of sex toys and mutual masturbation. However, many were uncertain about the safety of oral sex, particularly the specific safety of each different direction of cunnilingus and fellatio between a positive and negative partner.

Participants obtained safe-sex information from several sources, most commonly from HIV doctors or other health workers, followed by the internet, *Talkabout* and brochures at HIV or sexual health clinics. Only a few, mostly negative partners, had obtained safe-sex information from GPs but complained that they ‘don’t have a clue what they’re talking about,’ as Alice, 23, stated: ‘They told me it’s 100% that I’ll catch HIV.’ Some had received safe-sex education in prison or rehab.

Some said they found current safe-sex information too ambiguous, or else felt that it only addressed the physical nature of HIV and sex but not the emotional complexities involved in negotiating serodiscordant sexuality ‘on an

‘I think I pretty much basically know what one is supposed to do, or what one is not supposed to do. But do people follow this? I mean it’s down to what happens between the two people in the bedroom, isn’t it?’

ongoing basis, day to day, for the rest of your life’ (Olivia, aged 33, positive). Many did not keep up with safe-sex information because, as Sabrina, 46, put it: ‘Everyone knows that safe sex is condoms.’ But the pervasive emphasis on condoms among participants did not always translate into practice:

I think I pretty much basically know what one is supposed to do, or what one is not supposed to do. But do people follow this? I mean it’s down to what happens between the two people in the bedroom, isn’t it?

(Denise, aged 49, positive)

11 STIs = sexually transmissible infections

Among both positive and negative participants who had consensual unprotected sex with a serodiscordant partner, there was often a discrepancy between their definition of safe sex and their own sexual practice. However, they did not necessarily consider their sexual practice as *unsafe*, although a few did, with most relying on mutually agreed alternative risk-reduction strategies. Such strategies included withdrawal, putting a condom on before cumming, abstinence or condom use during menstruation or when the positive partner was sick, no anal sex and an undetectable viral load. These strategies were seen as reasonable precautions against the risk of transmission in light of current knowledge. A partner's ongoing HIV-negativity often reinforced the sense that the right balance had been found between safety and acceptable risk:

My attitude is, well, hang on a minute. I've been with this guy for five years and I still haven't got it. It can't be all that risky. And secondly, it's *not* easy to get. You've really gotta be serious about it if you want to get it, because it's such a fragile virus. It doesn't survive well outside the body.

(Claire, aged 40, negative)

It is interesting to note that, although the interviews were conducted prior to the controversial Swiss consensus statement (Vernazza et al., 2008), some couples who practised unprotected sex were already drawing on similar understandings of undetectability and reduced risk, with the one difference being that they believed an undetectable viral load made a positive partner *less* infectious, rather than non-infectious as claimed in the Swiss statement. Lydia, aged 44: 'I'm lucky at the moment, touch wood, because my viral load is undetectable and my count is good, so there's even less risk of passing it along.' Similarly, Mahmoud, 32, stated: '[A]t the moment because of my T-cells and my viral load is undetectable, so I'm pretty safe, you know.' Olivia, 33, had recently started to have unprotected sex with her negative husband in an attempt to conceive:

The first couple of times that happened I was stressing out. Like I was saying, 'Look, you know, I'll take you into the clinic and you can get some pills. You've gotta take 'em for a month.' And he's like, 'Look, the risk's low. You're undetectable. I know the score. Stop worrying.'

Several participants said that they had been informed by their doctor that an undetectable viral load made sex safer, although no doctor had endorsed it as a substitute for protected sex. It should be noted that in the case of all couples who practised unprotected sex, the positive partner was on treatments and had an undetectable viral load. However, not all positive partners who were

on treatments and had an undetectable viral load had unprotected sex. Nor did any couple state that an undetectable viral load was the reason for their decision to have unprotected sex. Indeed, it was difficult to ascertain to what extent an undetectable viral load was a driver of unprotected sex or to what extent it worked to reassure couples that what they were already doing was relatively safe.

Couples who had unprotected sex also emphasised monogamy as an important part of safer sex, another key aspect of the Swiss statement. Monogamy was seen as important primarily to avoid 'picking anything up from anybody else,' as Claire, aged 40, explained in reference to other STIs that could increase the risk of HIV transmission. But a few also alluded to monogamy as safe in that it contained both HIV and intimacy within the couple. As positive partner Mahmoud, 32, said: 'Just me and her. No one else. That's it. And that to me is safe sex.' Or as negative partner Gabriel, 44, put it: 'There's only the two of us. And we basically do what we want to do.'

Many who had unprotected sex also referred to the perceived low incidence of heterosexual transmission. Positive men tended to state that vaginal sex was far less risky than anal sex, while positive women and negative men tended to emphasise that the risk of transmission from a woman to a man was particularly low: 'Basically a heterosexual relationship between a male and a female where the female's positive, it's very, very, very difficult for the virus to be passed onto the male partner' (Gabriel, aged 44). Donna, 47, who is positive, summed up several themes:

I think that the likelihood is very, very, very remote ... And a health care professional, a professor, has said he would deny it if ever confronted, but that's what he believes also. So with that knowledge, with the knowledge that there's longevity now, with the precautions that I take with regards to my health—I don't have herpes and I don't have anal sex, so consequently, if I'm lubricated, then there's a very, very, very slim chance of contamination. And sixteen years [of unprotected sex] with my [negative] partner proved that ... Or whether it's just luck, whether we're playing Russian roulette, I don't know.

As hinted in this quote, while couples who practised unprotected sex would rely on a range of risk-reduction strategies, no one was confident that their sexual practice was completely safe and some were deeply conflicted. As we see in the next section, a range of complex emotions and dynamics around gender and serostatus were at play in the different sexual practices among the participants.

Protected and unprotected sex

HIV 'goes to the heart of your intimate life', observed Maria, aged 55. 'HIV is like the third party ... it does alter the dynamics,' Denise, 49, explained. Sexually active participants negotiated this dynamic through one of two strategies: protected sex and unprotected sex, each posing its own challenges. While this study sample is too small to draw out any distinct gender patterns, the findings suggest that unprotected sex among couples did not depend on the gender of the positive partner. This is consistent with other studies (see above). Yet, the meanings and practices of serodiscordant sex were deeply gendered. In addition, the positive women were more likely to have had *unprotected* sex with casual or short-term partners to whom they had disclosed, while positive men were more likely to have had *protected* sex with short-term partners to whom they had disclosed, or protected sex with casual partners, including sex workers, without disclosing.

Half the couples used condoms as an invariable part of their sexual practice. Their feelings and attitudes towards this strategy varied. Some saw condoms as a positive, uncomplicated choice. 'We just decided let's use condoms, and that's it,' said negative partner Stella, aged 44. 'I've got a lot of faith in condoms.' Along these lines, condom use was framed by a desire to adhere to a clear, consistent strategy to protect the difference in serostatus and peace of mind and thus facilitate a disentangled space of pleasure:

There's great clarity in having sort of a simple but total framework for sex, which is always use a condom. Because you can just get on with it. I'd hate to have to work out, every time we had sex, how we would do it. And, and just the anxiety after it. Awful. At least I know we've done what we could do. If anything goes wrong, there's no recriminations. There's no regrets. There's no, 'Well, we fucked that up, didn't we?' No. It happened. So if it does happen to me, I'll be fine on that score ... I have a lot of time for little bits of rubber. I think they're very good for your mental health ... They work. They're manageable, do-able. It's a positive act. You can do it. Everything else, really, is playing with your head.

(Maria, aged 55, negative)

Others framed condoms as a regrettable but non-negotiable necessity that they simply had to accept. A negative partner, Vikram, 27, observed: 'It used to be, in the beginning more, a bit of, a bit of a thought that, you know, the rest of your life you have to [use condoms], but that's the choice you make; it's just another challenge ... It has to be a part of it.' For some, condoms were a source of both comfort and frustration in that they worked to allay fears while also constraining intimacy. But this constraint could also open up other possibilities of intimacy:

[I]t's another one of the things that an HIV person has to adapt to, to change the way they have sex ... It's not easy sometimes. It's, there are some times where there are periods of frustration because I don't get to sleep with my partner or because things don't work out, or I don't work in the condom that day, but it's something I've just learnt to accept. Yeah. I suppose masturbation forms a great part of my life because of HIV now. I don't have any other choice. But I love to be with my partner and if I didn't have sex with her, I could still sleep with her, I could still cuddle her, I could still have a love life.

(Carlos, aged 37, positive)

Despite an initially lifelong commitment to condoms, some found that their position shifted as their circumstances changed. In the first phase of the study, Olivia, 33, described herself as a 'purist' with regards to safe sex and had made it a rule always to have protected sex with her negative husband. But they had recently made a decision to have unprotected sex around the time of ovulation to try to conceive after other methods had repeatedly failed. It was a decision and a new experience that she felt deeply ambivalent about:

And it's really hard for me because there's a part of me going, 'Stop it! Stop it! Stop it!' And then another part of me going, 'Actually this is really nice.' Mate, it's *really* hard. I mean it's really easy to sort of think at the beginning of a relationship, 'Yep, no worries, we'll just have protected sex. It's all fine.' But you kind of don't think about the other emotions that come into it, especially when you're thinking about having a family and, you know, how that theoretically is supposed to happen.

Half the couples did not use condoms consistently or at all. In addition, among those who were not currently in a relationship but who had been sexually active since diagnosis, nearly all had had serodiscordant sex, with over half having had consensual unprotected sex with a negative partner to whom they had disclosed. Studies have sought explanations as to why many serodiscordant heterosexual couples do not use condoms, exploring links between unprotected sex and, for example, duration of the relationship (Milam et al., 2006), illness symptoms (Skurnick et al., 1998), educational levels and drug use (Buchacz et al., 2001). But a review of the literature has shown that the results are so mixed and contradictory that this, in itself, is suggestive of the complexity of factors likely to be coming into play in serodiscordant relationships (Crepaz & Marks, 2002).

However, one important factor to consider is the cultural and gender dimensions of heterosex. Not only is penetrative sex normative, but research identifies persistent barriers to condom use among heterosexuals,

particularly among men (Moore & Parker Halford, 1999; de Visser, 2005). Studies with serodiscordant couples show that while unprotected sex is not associated with the gender of the positive partner (Skurnick et al., 1998; van der Straten et al., 1998; Buchacz et al., 2001), the most common reason given by couples for unprotected sex is the male partner's refusal to use condoms irrespective of his HIV status (Stevens & Galvao, 2007; Semple et al., 2002; Peretti-Watel et al., 2006; Dave et al., 2006; Milam et al., 2006). In this study none of the couples in which the man was positive cited this as a reason for unprotected sex, but several positive women raised the difficulty of getting a man to wear a condom. Denise, aged 49, spoke of past negative partners:

You bare your soul practically, you know. You tell them your life story. And they still sort of don't take the initiative of using condoms. So you know, it's sort of like one of those, it's a bit of a wank. Its, yeah, that's a tough one, really ... Because I want to have sex too. So it's tricky ... They can't use condoms. They can't come in them. 'It's really hard. It's awful.' You know, the whole story. 'I can't feel anything.' All of that stuff that they come up with.

One could argue that unprotected sex among some serodiscordant couples reflects a general lack of a language and culture around safer sex among heterosexuals, or that safe-sex messages are antithetical to a heterosexual ideology that links sexual spontaneity with romantic love (Ryan, 2000). Along these lines, unprotected sex could be interpreted as symptomatic of the cultural construction of heterosex as 'natural', as beyond change, rather than as a negotiated practice open to reinvention (Waldby et al., 1993b). The idea that condoms are incompatible with romance and 'normal' sexual intimacy was quite common among both men and women in the study. Said negative partner Claire, aged 40: 'I hate them. They're fiddly; you lose the moment. So we just don't [use them].' Corey, 48, who is positive, described condoms as 'another barrier to just *natural* sex'. Gabriel, 44 and negative, explained why he wanted to dispense with condoms:

Basically I love the woman ... And I just want to have a *normal* relationship. And that's it. So, yeah. And condoms are just so much messing around [laughs] ... We talked about it and I said, 'Well, look, you know, I just want us to be as we are and I don't want to mess around with all this rubbish.'

While these analyses are all clearly relevant to this study, they fail to capture the specificity of *serodiscordant* heterosexual relationships. Such relationships include not only the gender dynamics of heterosexuality, but also the interplay of HIV-positivity and HIV-negativity. This opens up another way of understanding serodiscordant sexuality.

Proxy negativity

Studies have found that intimacy with and acceptance by a negative partner can provide 'protection' from feelings of difference and stigma and thus a comforting sense of normality for a positive partner (Jarman et al., 2005). The findings of this study similarly suggest that serodiscordance enabled a semblance of heteronormality for positive partners. Having a negative partner who saw past their HIV status, past their 'spoiled identity' (Goffman, 1974), had the potential to destigmatise positive partners around sexual deviance by repositioning them, in their own and others' eyes, as 'normal' in identity and practice. 'It's wonderful to know that not everybody is hysterical about the disease,' said Donna, aged 47:

I met this chap in November last year and I told him in February this year. And he too has elected not to have protected sex because of my good health and because of the longevity and because he's not paranoid at all about it ... So it's a wonderful thing for me to have that acceptance. And [it] really has made some sort of *normality* in my life and not restricted me.

Being part of a serodiscordant relationship introduced a quantum of true HIV-negativity into the positive partners' lives, which diluted the perceived intensity and stigma of their HIV-positivity. This mixing of serostatuses made it possible for positive partners to assume a kind of 'proxy negativity', a desired state of redeemed heterosexuality in the absence of an even more desired cure for HIV (for

'I don't think I can [transmit HIV]. There's not enough in my blood to give it to [her]. The reason why I know this is because we've been together for three years. We've slept together for three years ... And she still hasn't contracted HIV ... So, draw your own conclusion from that.'

a discussion of proxy negativity, see Persson & Richards, 2008b). One way in which this proxy negativity was articulated was through the refusal of 'otherness' and a belief in the right to a place in an ordinary heterosexual world: 'It's not an issue for us,' said Mahmoud, 32, of his relationship. '[HIV] doesn't even come up. It's like we're a couple with no problem, no HIV, nothing. That's how we live our life now.' The viability of proxy negativity hinged to some extent on the absence of symptoms of illness and on effective medical suppression of the virus. But

its heteronormal purchase was contingent on a partner's continued HIV-negativity. As long as their partner remained HIV-negative, the positive partner was not transmitting a disease and thus evaded an infectious subjectivity:

I don't think I can [transmit HIV]. There's not enough in my blood to give it to [her]. The reason why I know this is because we've been together for three years. We've slept together for three years ... And she still hasn't contracted HIV ... So, draw your own conclusion from that.

(Mahmoud, 32)

The study findings suggest that proxy negativity operated in couples in two distinct ways, which seemed to play a significant role in why some practised protected sex and others did not. In some couples, serodiscordance tended to be explicitly acknowledged through communication or action, with the partners having worked out a structured and managed way of living together with differing serostatuses. A partner's HIV-negativity and its normalising power were safeguarded by carefully maintaining the physical boundary between the two serostatuses through the use of condoms. There was clear awareness of what was at stake for both partners should this boundary dissolve, as Maria, 55, explained:

I think part of our world would fall apart, because [Adam]'s sense of himself as a positive person has been really strongly built around the fact that I *am* negative, that he could make a relationship with a negative person ... and do it successfully. And that he can *keep* me negative. Because he handles the condom, I don't. Even though we both engage in the decision-making, ultimately he looks after it. So his prowess and his ability to care for me, and his ability as a man ... even though he can't advertise that, it's very important to him ... For me, to remain negative, it's incredibly important because it's been a long, hard battle to make that relationship. And I've lost a lot because of the choice I made to have the relationship. So I don't want to lose the fundamental in HIV, which is your serostatus. Mine is negative. I don't want to lose that, because it's a daily act to keep it. And it means always having safe sex.

In other couples, there was a blurring of serostatuses or, more precisely, a 'disappearing' of HIV-positivity into HIV-negativity and its reassuring heteronormalcy. This disappearing effectively removed any rationale for practising protected sex. Mahmoud, 32, spoke of his partner's acceptance of him and her apparent lack of concern about the virus: 'She doesn't even bring me close to even thinking—like I don't think nothing about it when I'm with her.' His partner Lowanna, 25, was aware of how she enabled this proxy negativity: 'I don't live my life around [HIV] ... And he thanks me every day that I don't live like that.' In contrast to Maria and Adam, Lowanna

and Mahmoud protected this sense of heteronormalcy not by intently keeping their serostatuses apart, but by jointly erasing HIV from their relationship, including from their sexual life: 'I don't withdraw out or anything,' Mahmoud explained, 'just *normal*, like there's nothing wrong.'

The fact that Mahmoud had remained healthy since he had tested HIV-positive, and was doing well on treatments, reinforced the 'unreality' of HIV. 'To me, every day living with him ... I *never* think he's got HIV,' Lowanna said, insisting that: 'I won't change the way we live our lives ever unless he gets sick. Like if his medication's not working or something, *then* we'd start dealing with it. But why deal with something *that's not there*?' The couple's investment in heteronormalcy was shored up by a shared belief either that Lowanna was somehow immune to HIV, having remained HIV-negative, or that Mahmoud somehow did not really have HIV, as Lowanna hinted:

We have sex on a daily basis and we never use protection ... We never use protection and we've had a baby, and look at us. So, it's amazing ... I just get this feeling all the time of he just doesn't have it ... Until he starts showing me some sign that he actually has HIV [laughs], I will always have unprotected sex with him.

For this couple, then, unprotected sex became an act of affirming sameness, not difference. This act did not constitute a potential transmission of serostatus from him to her, but rather from her to him, the lack of barrier enabling him to *be like* her, to absorb her HIV-negativity. And at the same time, because of the surrogate nature of proxy negativity, complete safety was never assured. 'It's like we're gaming a little bit, you know?' Mahmoud stated. 'We're playing with fire.' This statement leads us into the next sections, which explore the tensions and complexities around sexual negotiation and responsibility.

Negotiation and responsibility

Well, you theoretically negotiate it. And everybody knows what's going on. And you're very informed. And you decide beforehand what you're going to do and what you aren't gonna do, and what the boundaries are and aren't. But nobody thinks about the emotions that are involved during that time. And what things come out of the blue that you don't expect, and complications that make everything a lot more difficult than you thought it would ever be.

(Olivia, aged 33, positive)

In couples who practised protected sex, sexual safety tended to be positioned as a necessity by both negative and positive partners or else was driven by a strong sense of responsibility on the part of the positive partner. Several positive partners emphasised that they would not agree

‘My partner now would have unprotected sex with me if I permitted it ... And for me, counting on 20-minute pleasure; it just doesn’t work out for the heartache of, and how I’m gonna condemn myself later, how I’m gonna feel. So I just, I really feel really strongly about that.’

to unprotected sex if their negative partner wanted it, because they did not want to put their partner at any risk, no matter how small, as it would cause too much worry and stress. One negative woman said: ‘Even if I didn’t want to use condoms, he would have, no, no, wouldn’t hear about it. “We *must* use condoms.”’ For Carlos, 37, sexual strategy was not a mutual or negotiable decision:

My partner now would have unprotected sex with me if I permitted it ... And for me, counting on 20-minute pleasure; it just doesn’t work out for the heartache of, and how I’m gonna condemn myself later, how I’m gonna feel. So I just, I really feel really strongly about that.

Among couples who practised unprotected sex, the notion of responsibility tended to be more ambiguous and complex. Most positive partners resisted discourses that placed responsibility squarely on them and divested the negative partner of agency in sexual decision-making. One positive man said: ‘I don’t wanna be responsible for giving her HIV. And then at the same token, if you don’t want to be responsible, why don’t you use [condoms]? I can’t explain that because it’s, um, it’s not only my choice.’ Another positive man stated: ‘I go back to that it’s informed consent ... I believe everybody is responsible for their own life.’ But several positive women described how their partner’s refusal to wear condoms complicated both sexual negotiation and the idea of responsibility:

My last two relationships, with both the men I’ve disclosed, very, from an early stage, and neither of them have been too perturbed about wearing condoms ... I’ve told him what I’ve got. I’ve told him the risks. I’ve told him to go on the internet. I’ve told him to whatever ... [W]here I get confused is, whose responsibility is it then? ... I cannot force someone to wear a condom. And so then I have to look at it, well if they’re not gonna wear a condom, do I just not have sex for the rest of my life?

A longitudinal study with serodiscordant heterosexual couples in the US claimed that negative partners were often more willing to take sexual risks than their positive partners (van der Straten et al., 1998). A surface reading of the Straightpoz data suggests the same. In couples who

had unprotected sex, the decision to do so was framed by both partners as the negative partner’s choice. Denise, 49, said: ‘With negative people it’s been entirely their choice.’ Negative partner Gabriel, 44, stated: ‘When we first got together we practised safe sex for a period of about two weeks. And haven’t since. That’s *my* decision.’ Lowanna, 25, said of her decision to have unprotected sex with her positive partner: ‘This is *my* choice; I’m making this choice and I want to.’

Negative partners cited love, sexual pleasure, dislike of condoms and knowledge of the risks as the basis for their choice. However, their decision to have unprotected sex was sometimes entangled in far more complex emotions or was part of a delicate balance in a relationship. For example, one woman explained that her positive partner was much happier when he did not think about HIV: ‘When he lives his life like he has HIV he gets very depressed. I’ve noticed that about him.’ She said that she avoided drawing attention to HIV or doing anything that would remind him. When asked if this included having unprotected sex, she pondered:

Subconsciously I must do that for him so he can feel better about himself, because I know things affect him really badly ... he isolates himself, and he feels so disgusted about himself. And I *hate* the fact that he feels like that. So I try in every possible way not to make him feel like that.

Positive partners, on the other hand, tended to frame their negative partners’ decision in terms of knowledge. They emphasised the importance of their negative partners’ being educated and fully aware of the risks of unprotected sex to ensure that their decision was an informed one. Corey, aged 48, explained:

I believe that we practise unsafe sex, but it’s something that [she] has, I think, has a full understanding of what we do. And it’s, I don’t always feel comfortable doing it. She seems to be prepared to accept that risk. She knows of the risk. She’s been to information sessions and, as I was saying earlier, I think is very well informed. She’s done a fair bit of reading. And I would prefer that she didn’t take that risk.

As hinted at in this quote, while the emphasis on negative partners’ informed choice worked to shift the onus of responsibility in a couple, positive partners were often deeply ambivalent about unprotected sex. Many described a tension between the emotional and sexual pleasures of unprotected sex and the ambiguity of responsibility. Underneath the idea of informed choice often lurked an ongoing sense of uncertainty. As Olivia, 33, put it: ‘Have I talked about this enough in the past that he’s informed enough to make his own decision, and do I just let him make his own decision? Or do I not?’ She continued:

There's a part of me that goes, 'You should just stop doing this completely because it stresses you out and, you know, it may have a bad, it may have, you know, a horrible impact for him.' But then there's another part of me that goes, 'Well, OK, yes that's true. But he's saying he's enjoying it. And I'm actually enjoying it.' So *where* do I draw that line? And given that he's my husband, it's *really, really* hard ... And it's something that I am struggling with a lot. And I honestly don't know the answers to it. I wish I did.

Some positive women also expressed doubt about the validity or acumen of their partners' decision to have unprotected sex. Denise, 49, said: 'I've got no idea how they negotiate with themselves. I don't think they do. I think men think with their dicks, and that's it.' Despite assurances by their negative partners that the negative partners took full responsibility for their own lives, many positive partners struggled to reconcile their partners' sexual choice with the ultimate responsibility for transmission. To cite Denise again: 'I have felt a little bit uncomfortable when they haven't [used a condom]. Because then the onus of possible seroconversion to them has been on me, even though it's not.' Lydia, aged 44, elaborated:

I've learnt now, as long as I've done the right thing and I've disclosed and I've made them aware there is still a risk factor even though it's minimal, it's up to them. But I mean it's still, even though I do all that ... it still doesn't sit right with me because I know there is that slight risk. And in fact if that person *did* get it, I then would have to live with the guilt. And even though people say, 'Yeah, but it was their choice,' yeah, it might have been their choice but, I'm sorry, I would *still* have to live with the guilt.

This ambivalence might explain a curious discrepancy between many partners' accounts of unprotected sex. Most negative partners were under the impression that their positive partner was at ease with their sexual practice. As one negative man said: 'Yeah, very comfortable; she's fine with it ... It's not, it's not a major issue. Well, it's not for me.' But many positive partners said that they wished their negative partner would 'insist on condoms'. One positive man said: 'I would like to use [condoms] ... because it would make me feel better.' Another said: 'When you think of it rationally, I think that she is silly to take that risk.' One of the positive women elaborated:

I just pray that, because my viral load is undetectable and that, that I don't pass it [on]. But you never know. And that's, you know, that's why I'm like, 'For God's sake, man, put a condom on. It's not that hard.' I mean it's still gonna, you know, sex is sex. And yeah, to me it's not gonna really make that much difference. But obviously men have this thing about condoms ... I would prefer [him] to wear condoms.

This discrepancy is open to interpretation. It no doubt indicates the difficulties couples had in navigating the fraught terrain of sexual intimacy and responsibility. It is also possible that positive partners wished to present themselves as responsible sexual subjects in the interview by noting their discomfort with unprotected sex. At the same time, fear of transmission was a common theme among positive participants, while it seemed curiously absent in the negative partners' interviews, as discussed in the next section.

The spectre of transmission

Many positive participants expressed a sense of dread about the possibility of transmitting HIV. Several spoke about recent legal cases in Australia involving male defendants charged with transmission of HIV (Persson & Newman, 2008). The threat of legal repercussions, along with the difficulties of negotiating disclosure and sexual practice, weighed heavily on the men in particular and posed a barrier to seeking an intimate relationship with a negative partner. Consequently, several men chose sex that circumvented some of these challenges. As Angus, 53, put it: 'I'd rather stick a condom on and go up the bloody brothel up the street here.' Victor, 34, elaborated:

I've had sex since I've been positive. Sure I have. But when it comes to someone that you know and they're trying to connect with you, and you know damn well they're negative, wow. It's chilled me to the bone. I'll admit it. And it's got me to the point where I just don't want it to progress any further than friendship. Don't want a sexual liaison. Just *too* scared ... If she ever seroconverted, I know who the culprit would be. And I've put myself through enough trauma and my parents, to have to go and face court hearings, especially when it would not necessarily be your fault. You know? No, it's just too spooky. I'll stay away. I'll stay celibate [laughs]. Or you know, pay to go and see a [sex] worker.

Among couples, positive partners' fear of infecting a negative partner was a much more common theme than negative partners' fear of becoming infected. Positive partners, especially those who had unprotected sex, often

'I always have the thought, "I don't want to give this virus to anyone." So, I mean, that's in whatever, in any relationship I have with someone who's not positive ... I always have that fear there. You know what I mean? And it will always be there. Always.'

conceded that the possibility of transmitting HIV played on their mind. 'I can't see how anybody could *not* have that in their mind,' noted Corey, aged 48. It was a possibility that haunted serodiscordance and threatened to undo the proxy negativity it provided. Mahmoud, 32, said: 'To be honest I feel, I get scared for her because I really don't want her to have HIV. You know? Because it would make me feel real ugly.' Similarly, Angus, 53, stated:

I always have the thought, 'I don't want to give this virus to anyone.' So, I mean, that's in whatever, in any relationship I have with someone who's not positive ... I always have that fear there. You know what I mean? And it will always be there. Always.

Given this unalterable possibility, the relinquished condom performed a paradoxical role. Its absence at once negated and evoked the idea of infectivity, at once enabled and counteracted heteronormal sex, which might explain why positive partners often felt conflicted about unprotected sex. Corey, 48, described the tension between sexual pleasure without condoms and the spectre of transmission:

I guess having [unprotected] sex puts on me certainly a whole lot of mental pressure, and it's possibly not as enjoyable as it could have been if you didn't have to worry about not trying to infect someone ... It's certainly more enjoyable without using condoms or things like that. But it's just an area that, it's enjoyable but you've got a mental pressure. So there's a physical pleasure and a mental barrier. And so I guess it's riding between the two.

The absence of an articulated fear of infection among negative partners was more difficult to interpret. Regardless of their sexual practice, most negative partners stated that their positive partners were far more worried than they were about transmission, which is consistent with other studies (van der Straten et al., 1998). Alice, 23, said: 'I think he worries about it *heaps* more than me, which he shouldn't ... I'm a big girl; I make my own decisions.' Yet, in the narratives of some negative partners who had unprotected sex, the spectre of transmission seemed dislocated rather than missing. This dislocation seemed to arise from the positive partner's being positioned in particular ways, which in turn worked to position the negative partner as sexually safe by implication. For example, some strongly rejected any positioning of their positive partner as infectious:

Like every time I sleep with him, I've never got that tiny thought, not even a slight thought in the back of my mind, 'Oh, he's got HIV.' Never, ever. 'Oh, this might be the day I'm gonna get HIV.' I've *never, ever* thought it. From the day I slept with him, knowing that he had it, I've never thought about it.

(Lowanna, aged 25)

Others strongly resisted narratives that positioned their positive partner as irresponsible or careless. They emphasised that their positive partner would never intentionally put them at risk: 'He's very good in withdrawal, *well* before,' said Claire, aged 40. 'I completely trust him with that because I think he would be absolutely devastated if he passed it on to anybody ... So I don't have any qualms about that.' Yet, a few moments later, Claire's lack of qualms was tempered by a more ambivalent statement, indicating that the spectre of transmission was not absent from her narrative:

In the cold light of day I think, 'I should never do that again. Always use a condom.' But then when the moment hits, you never do. It's just too much hassle.

Alternatively, a few negative partners resisted narratives that positioned HIV as a dangerous disease. They tended to articulate a fatalistic approach—'if I get it, I get it'—and explained that HIV was no longer the disease it once was. They referred to the availability of effective treatments and to the healthiness of their positive partner as proof of this. Gabriel, 44, said this about the possibility of transmission:

[I]t doesn't bother me. Honestly. Don't worry me at all. And, seriously, even if, OK, if I did a test next week and I am positive, it's not a death sentence. Not at all. And with today's medicine the way it is, it's not even gonna dramatically shorten your life that much ... [L]ook, if I was that obsessive about it I wouldn't be with somebody who's positive. I mean, if I was obsessed about it, like, 'Oh my God, am I gonna get it?' I wouldn't be with someone that has it because it would increase my chances of getting it. It stands to reason. No, it's not such a major concern.

Some negative partners were undoubtedly genuinely unconcerned or felt genuinely safe in their sexual practice. But it is also possible that some played down any fears on their own part as a coping mechanism or out of loyalty to their partners. Only one negative partner divulged fears of becoming infected and tellingly revealed how such fears could create tension in a couple. He attributed his fears to alarmist misinformation given by a GP early in his relationship, which 'scared the hell out of me'. He later received more accurate advice from sexual health workers, but 'because of the wrong information [initially] provided to me, there's still kind of fear inside'. He recognised that his fear was 'irrational' and hurtful to his positive partner in that it positioned her as excessively infectious. She said: 'I wish that it, you know, it didn't have to be like that ... and he knows, you know, how I feel ... I don't let it get to me. But sometimes it does.'

HIV-negativity and HIV testing

In many negative partners' interviews, the refusal of fear existed in tension with an express desire to remain negative. For some, this desire was reinforced by having seen the detrimental effects of HIV on their positive partner. The women's narratives tended to be gendered in the sense that they wanted to stay 'healthy' so they could care for their positive partner or their children. Also, they often expressed more concern about how transmission would affect their positive partners rather than themselves. Alice, 23, said: 'I think if anything were to happen, I think it would affect him a lot ... it would definitely impact his life too much.' Others emphasised the stigma and social marginalisation of being HIV-positive. Stella, 44, described how she felt while waiting for the result of her second HIV test, convinced that it was going to be positive:

I felt for those three months as if I was sort of behind a glass screen. Like you sort of become 'the other' ... I felt that I was looking at the world as an observer. And as if you couldn't participate in such a full way as before. Or you'd be excluded, or whatever. But yes, so when I found out it was negative, it was good news.

Yet most partners found it difficult to articulate what it meant to them to be HIV-negative. This might be explained partly by a general lack of cultural and communal forms of dialogue around HIV-negativity, and partly by the fact that their serostatus was inextricably bound up with HIV-positivity by virtue of their serodiscordant relationship. Claire, aged 40, hinted at this when she described her serostatus as normal, and yet not:

I'm normal ... To be negative means that I have a normal life. To be in a positive-negative relationship is not normal, and that I find a bit, um, challenging I suppose. Especially considering that it's not something I can talk about [to anyone].

For those in serodiscordant relationships, HIV-negativity is a serostatus that is lived in the immediacy of HIV, not in its absence. As such, it is a serostatus that is distinctly different from that of other people who are not HIV-positive yet it is rarely acknowledged as such. 'HIV-negativity' is often taken to be synonymous with all people who are 'not HIV-positive', allowing no distinction between those who have no contact with HIV in their daily lives and those who do. Maria, 55, referred to HIV-negativity as invisible when she described what her serostatus meant to her:

My negative status is *never* valued, never validated, never recognised *anywhere*, even in the sector, let alone in normal life ... All those campaigns with posters and so on; I'm it. And I'm treated as though I'm just like anybody else with the same chance of being infected by HIV, whereas my chances are much higher ... all

of that's ignored. Plus the wear and tear on me that HIV is having isn't examined ... So I'm standing next to someone I love with all my heart and I don't have the thing that he does have. So that's the first thing ... It also means that when I go to the sector, I will be blatantly ignored by all and sundry. So I don't exist. So I am negative. I'm in a non-space, a negative space, in the true sense of the word.

Adding to the elusive quality of HIV-negativity is the fact that serodiscordant sex is a portal of potential identity change for negative partners. As a consequence, partners can inhabit a space of uncertainty, a kind of liminal serostatus of 'not knowing' between HIV-positivity and HIV-negativity. Three years into his relationship, Vikram, aged 27, had not yet had an HIV test and was torn between wanting and not wanting to know his status:

I haven't still been able to get myself tested. I'm living in a limbo ... I never had the courage. And I thought, 'If something has happened, it has happened' and I don't want to face it; I try to run away from it. But it never affected my love for [Ruby]; it's always been there and it will always be there ... Eventually it will have to happen, if not today, tomorrow, or, because decisions have to be made and I can't go on like this forever. Eventually, and I'm trying to gather the strength for it [laughs] ... But it does, yeah, when there is no answer, it does put me emotionally down a lot. Like what's, what's my status? I don't know.

This liminal serostatus is not necessarily easily resolved by testing. For sexually active partners, an HIV test will confirm only that they were HIV-negative some weeks before the test was taken but not whether they are still HIV-negative in the present moment. Therefore HIV-negativity is not a conclusive serostatus identity but a fundamentally ambiguous one. Together with a sense of being invisible in the HIV sector and in society more broadly, some negative partners experienced this as a loss of identity or as a kind of non-identity. Maria, 55, explained that she had stopped having tests because they did not really mean anything and she did not want to be reminded of her non-identity:

I don't get tested. I don't. It's pointless ... [A]ll the test does is say to me that I'm a 'non-person'. Yeah, the knowing and not knowing. Because the test, there's that, the gap of three or four months or whatever it is, where you could have become infected. Why are we here? I'm wasting my time ... The test is not a good test. It reinforces non-identity, yeah. And I don't need that. If I don't test it's one less thing that reminds me of non-identity. Non-identity is a daily reality for me. Every day I go to work and I practise my non-identity. So to

trot along to a local health provider and be medically told that I don't have any identity, I don't need that.

Conversely this non-identity sometimes compelled even partners who were not sexually active to repeatedly test for HIV. In the first phase of the study, Katya, then 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'. She reiterated this in the second phase of the study, saying that 'I think it's better to know than don't know'. Similarly, Phoebe, 36, had had five HIV tests since her husband's diagnosis 18 months ago, despite no longer having sex, 'just to see it in black and white'.

Most partners, however, did not test regularly although most had had an HIV test at some point in the past. As mentioned, some saw the test as meaningless or, conversely, as too terrifying. Others rationalised that regular testing was not necessary if appropriate precautions were in place, while some did not see it as a priority. The reassurance of persistently negative tests was another reason for reducing the frequency of testing. Some couples' investment in heteronormality turned the test into a foregone conclusion. Lowanna, 25, explained why she never worried about the results:

Not me, man. Nah! I don't. I go in there and get it done. That's it ... I just know when they're taking the blood out, I *know*, I'm 100% guaranteed that they're gonna, they're not gonna ring me. And I know that it's gonna be all right ... The second I walk out of the hospital it's gone out of my head again.

A desire to not treat their positive partner as infectious might also explain why some negative partners did not regularly test for HIV and, indeed, why a few tested themselves more often than they actually admitted to their

'So every now and again I say, "Maybe you should have a test just for, you know, everybody's peace of mind." He's just like, "Why?" ... I think I'd have to drag him kicking and screaming. I honestly do ... How I read him is that he's not worried about it. *I'm* the one who's worried.'

positive partner. In contrast, the lack of testing by negative partners was often a source of anxiety for positive partners. Many would urge their negative partners to be tested and were often bewildered by their seemingly casual approach.

Lydia, 44, said: 'This is, the hardest thing I find with having [HIV] is that I can't make the other person do something. I can suggest and I can, but I can't actually make him, grab his hand and, and pull him up there [to the clinic]. But it always is in the back of your mind.' Olivia, 33, said her husband's last test was over four years ago:

So every now and again I say, 'Maybe you should have a test just for, you know, everybody's peace of mind.' He's just like, 'Why?' ... I think I'd have to drag him kicking and screaming. I honestly do ... How I read him is that he's not worried about it. *I'm* the one who's worried. But, you know, I'm not objective about it. I don't know how realistic or unrealistic I'm being ... I mean if he was tested I'd actually expect it to be negative. But by the same token it'd be nice to have that negative test and be sure about that.

The uncertainty of a negative partner's HIV status worked against the proxy negativity and heteronormality that serodiscordance provided positive partners. One of the men's reluctance to have an HIV test was a point of tension in his relationship. While the chances of his actually being positive were minimal considering the couple had always had protected sex, his ongoing anxiety over his unknown HIV status meant that his partner was continually reminded of her own:

I can understand, I can see why he doesn't [test], but it's just, his reaction just makes it more difficult to live with ... I'm a person, I'm a person, you know ... And therefore, these things just keep reminding me, reminding me, reminding me ... I just want to live my life.

But testing worked both ways. The act of testing had the capacity to similarly disrupt heteronormality by bringing HIV into focus in a relationship, which suggests why positive partners sometimes had ambivalent feelings about testing, as Olivia, 33, explained: 'I suppose I would like him to have a test. But by the same token [sighs], sometimes it's nicer not to know.' Some positive participants were quite comforted by their negative partner's disinterest in testing and framed it in romantic terms. Tobias, 53, spoke of his previous partner with whom he had had unprotected sex for seven years:

She used to have a 'what will be, will be' attitude. And I used to [think], what would I have done if the positions were reversed? I would have been with her and I would have had sex the same way with her. And the other thing was that I was deeply in love with her ... I know that sounds childish and, you know, Mills and Boon romance, but I can understand that. Yeah, she chose not to [test]. She chose not to for her reasons. The opportunities were there and she'd come to the clinic with me often.

A lack of suitable health services for negative partners might be another barrier to testing. A few partners had their tests done at their positive partner's HIV clinic but such clinics are primarily focused around the health needs of HIV-positive patients. Most partners went to general practices for their test but such practices are rarely HIV-literate and, as described in Chapter 3, not always sensitised or sympathetic to a negative partner's situation. It is also noteworthy that most serodiscordant couples had a rather vague awareness of post-exposure prophylaxis (PEP)¹² or else did not see it as relevant to them, either because they always had protected sex *or* because they always had unprotected sex: 'I'd be having PEP shots every day,' laughed Gabriel, 44. 'No point.' None of the negative partners interviewed had used PEP and only three positive partners said that their negative partner had used PEP, and only once.

There was no obvious parallel between HIV testing and unprotected sex. In both phases of the study, regular and non-regular testing was fairly evenly distributed among couples who had unprotected and protected sex or no sex at all. This seems indicative of the multiple and complex factors at play in partner testing. It also indicates that more work is needed not only to facilitate information and communication among serodiscordant

couples but, perhaps more importantly, to find ways to engage negative partners that acknowledge and validate their unique experiences as people who 'live with HIV' in their own right. As the findings suggest, for those in sexual relationships with HIV-positive people, being HIV-negative is not necessarily experienced reductively as simply an absence of HIV as evidenced by a medical test; it is defined by, and does not exist outside of, their intimate relationship with their HIV-positive partner.

Because of their limited contact with others living heterosexually with HIV, most couples in this study operated in a kind of social vacuum with little sense of how their sexual practice compared with that of other serodiscordant couples. Zoe, 26, stated: 'I have no idea, with other couples, how they are, I don't know. I haven't really discussed anything with anybody ... I don't know how it fits with how others do it.' Many were curious, including Corey, 48: 'I hope that somewhere in your research you document what other couples do ... To think that I'm a freak, or we're freaks, or we're somewhere around average ... It would be great to know what is normal and average.' Many speculated that unprotected sex was probably more common than expected because of 'the heterosexual aspect of it', as Lydia, 44, said. Interestingly, irrespective of their own sexual practice, many emphasised that other couples *should* practise protected sex. As this chapter illustrates, that some did not do so themselves is no doubt indicative of the complexities of negotiating sexual intimacy in a serodiscordant relationship.

12 post-exposure prophylaxis (PEP) = a treatment procedure used to reduce the risk of infection after potential exposure has occurred

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Persson, A., & Richards, W. (2008). Vulnerability, gender and 'proxy negativity': HIV-negative women in serodiscordant relationships in Australia. *Social Science & Medicine*, 67, 799–807.

Abstract

In contemporary international HIV discourse, women are positioned as especially vulnerable to HIV. This vulnerability is ascribed to gender inequality and its many structural, social and sexual manifestations. It is an important discourse in that it foregrounds how the realities of women worldwide constrain their ability to control their lives and bodies and, consequently, their ability to protect themselves against HIV infection. At the same time, its analysis rarely exceeds a generalised description of gender and power and, as such, fails to usefully engage with the specificity of serodiscordant gender relationships. Drawing on qualitative interviews with HIV-negative women and their HIV-positive male partners, who participated in a larger study on HIV and heterosexuality in Australia, we argue that without a considered analysis of the gendered interplay of differing HIV statuses, the vulnerability discourse remains limited in its capacity to capture the diverse, complex ways in which these HIV-negative women negotiate HIV in their sexual lives, how they are positioned in their relationships, and how vulnerability can figure in less obvious ways. We discuss how gendered meanings invested in the women's HIV-negative status constituted a powerful conduit to heteronormality for their male partners. The mixing of serostatuses made it possible for the men to assume a kind of proxy negativity, a desired state of redeemed masculinity. We explore two ways in which this proxy negativity operated among the couples and shaped their sexual practices. As a result, this paper makes an important contribution by showing how vulnerability to HIV infection can hinge on the different ways serodiscordant couples manage gendered meanings around serostatus emotionally and sexually.

Persson, A., & Richards, W. (2008). From closet to heterotopia: A conceptual exploration of disclosure and passing among heterosexuals living with HIV. *Culture, Health & Sexuality*, 10, 73–86.

Abstract

This paper explores how experiences of disclosure and passing among heterosexuals living with HIV in Australia can be meaningfully conceptualised beyond therapeutic discourses and habitual metaphors. It engages in a dialogue between qualitative research material, HIV disclosure literature and theory. It is first argued that an emphasis on the therapeutic value of disclosure in much of the literature obscures the complexities of HIV stigma as socially produced and lived. Next, the paper considers the concepts of 'the closet' and 'coming out', which have become shorthand for a range of social stigmas. Although parallels are found between the productive effects of the closet and the research material, the idea of 'coming out' fails to capture the cultural context of HIV in Australian heterosexual society. This raises questions about the contemporary tendency to invoke the closet as a presumed universal metaphor. Foucault's idea of heterotopia is proposed as an alternative way of conceptualising the lived worlds of disclosure and passing in this research study, with the hope of opening out future discussion and theorising.

Persson, A. (2008). Sero-sharing and sero-silence: Managing HIV in serodiscordant heterosexual relationships. *AIDS Care*, 20, 503–506.

Abstract

Research shows that couples with differing HIV status can face a number of social, sexual and relationship challenges. Communication is often emphasised as the key to couples' ability to cope with these challenges. Silence by implication becomes positioned as inherently negative, even dysfunctional. The privileging of communication as proper therapeutic adjustment to illness forecloses consideration of the complexities of managing HIV as a serodiscordant couple, let alone any enabling aspects of silence. Drawing on qualitative research interviews with HIV-serodiscordant couples in Australia, this article examines the usefulness of this polarisation between communication and silence and explores alternative ways of understanding silence that might offer useful tools for HIV health workers and researchers.

Other publications on HIV and heterosexuality by Asha Persson

Persson, A., & Newman, C. (2008). Making monsters: Heterosexuality, crime and race in recent western media coverage of HIV. *Sociology of Health & Illness*, 30, 632–646.

Abstract

In the early HIV epidemic, western media coverage encouraged the idea that infection was linked to 'other' identities located outside the 'mainstream', outside 'proper' heterosexuality. Today, however, HIV has become repositioned as a global heterosexual epidemic. Analyses show that since the 1990s western media have shifted away from blame and hysteria to an increasingly routinised reporting of HIV as a health story and social justice issue. But recent years have seen the emergence of a new media story in many western countries; the criminal prosecution for HIV-related offences, and with it a reframing of old discourses of 'innocence' and 'guilt', but now with heterosexuals in focus. We examine this story in recent domestic media coverage in Australia, a country where heterosexual HIV transmission is rare by global comparison. Echoing similar stories in other western media, in Australian coverage the idea of criminal intent converges with the symbolic weight of black sexuality and African origins to produce a 'monstrous' masculinity, which at the local level taps into contemporary racial tensions and, in so doing, conjures an imagined Anglo-heterosexuality at once vulnerable to and safe from HIV in a globalised epidemic and world.

Newman, C., & Persson, A. (in press). Fear, complacency and the spectacle of risk: The making of HIV as a public concern in Australia. *Health: An Interdisciplinary Journal for the Social Study of Health, Illness and Medicine*

Abstract

This paper explores how HIV is constituted as a matter of public concern in Australia, where —unlike much of the rest of the world—there is a continuing low incidence of heterosexual transmission. In this context, it is timely to explore how the media contributes to the ongoing mobilisation of public interest in HIV, and how heterosexual audiences are brought into focus as the imagined 'publics' of mainstream debates on HIV. This paper identifies three approaches to generating public concern in HIV news stories published in *The Sydney Morning Herald* between 2000 and 2005 as well as in academic media analysis and HIV education and advocacy. Reflections on fear revisit the early years of the epidemic, distinguishing a generation of Australian audiences shaped by the Grim Reaper campaign. Encounters with complacency focus on an apparently widespread lack of concern about HIV in the present. And projections in risk forecast a multiplication of HIV risk environments, despite confusion about who should be personally concerned about those risks. Together they construct Australian publics as passive, vulnerable, unaware and potentially uncaring, yet do little to engage the mainstream as more than spectators of public concern about HIV.