

Taking post-exposure prophylaxis: Managing risk, reclaiming control

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Taking Post-Exposure Prophylaxis

Managing risk,
reclaiming control

PEP

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RESEARCH PARTICIPANTS

The 88 men and women who gave in-depth accounts of their experience with PEP

KEY FINDINGS

- Incidents that lead to potential HIV exposures are usually characterised by a temporary absence of control—rather than a lack of it. PEP becomes a means of restoring order and reclaiming control.
- Rational decision-making and reasoning—about sexual practices, taking treatment, and disclosing—are confounded by the somewhat messy reality of the physical, social and emotional contexts in which exposures occur.
- Relationships are often cited as contexts for incidents that lead to potential HIV exposures: ongoing conflict in regular relationships, vulnerability after relationship break-ups and the uncertainty surrounding new relationships.
- In serodiscordant relationships, clinical markers are often factored into sexual practices and into risk assessment after a potential exposure.
- HIV-positive and HIV-negative gay men have different knowledges and attitudes in relation to clinical markers and UAI. For positive men, infectivity and risk assessment is based on their knowledge of clinical markers, where undetectable viral load means reduced infectivity. For negative men, risk assessment is based on the public health message of using a condom. (*None of the participants in this study relied on the possibility of reduced infectivity of a positive partner with undetectable viral load. All decided to take prophylaxis.*)
- There can be multiple understandings of the concept of “shared responsibility” around the negotiation of sexual practices and condom use. For a positive man it can mean taking the receptive position in UAI with a negative partner. For a negative man it can mean disclosure of serostatus and using a condom.
- Participants in this study generally perceived PEP in the same way as it was intended by health authorities—as a means of reducing the risk of HIV infection when other strategies have not worked, i.e. as a back-up rather than a replacement for other strategies such as condom use.

RECOMMENDATIONS

- HIV education should take into account the different experiences and expectations of older and younger gay men.
- Future prevention messages should also address the social and emotional contexts in which exposure to HIV can occur.
- HIV prevention for gay men in relationships needs to address the particular vulnerabilities to HIV that exist for gay men who have recently ended a long-term monogamous relationship, as well as men who are experiencing conflict within their current relationship.
- Education programs should develop models that provide support for people on PEP that do not depend on disclosure of taking PEP (or UAI) within their existing social networks.

INTRODUCTION

Whether or not anti-retrovirals administered immediately after exposure to HIV infection can prevent HIV infection remains contentious. Nevertheless, data from studies in animals (Tsai et al., 1995), observational studies in health care workers (Cardo et al., 1997), and randomised controlled trials of the prevention of mother-to-child transmission of HIV (Guay et al., 1999) all suggest that post-exposure prophylaxis (PEP) may be effective in preventing HIV transmission. A randomised controlled trial in the occupational setting was attempted but was unable to recruit, probably because of a perception that it was unacceptable to randomise individuals to the non-receipt of PEP. Nevertheless, in industrialised countries, PEP has become standard of care after occupational exposures to HIV (CDC, 2001).

In contrast, there has been considerable controversy over the introduction of PEP after non-occupational exposures. Worldwide, Switzerland was the first country to publish recommendations on non-occupational PEP in December 1997 (Bernasconi et al., 2001) followed by Australia (NSW Health, 1998) and several other European countries. In the United States, feasibility studies have been performed (Kahn et al., 2000), but guidelines do not recommend for or against this therapeutic approach (CDC, 1998). In some locations, PEP for non-occupational exposure is available in limited circumstances such as in cases of rape.

The main reasons for the delay in introducing PEP for non-occupational exposure have been concerns regarding the lack of efficacy data, the fact that the HIV status of the source person is often unknown, there is often a delay in initiating PEP, drug toxicity, and potential undermining of behavioural HIV prevention strategies.

BACKGROUND: COHORT STUDY

The in-depth study described in this report is a part of an ongoing prospective cohort study initiated to monitor implementation of guidelines recommending PEP for HIV in the context of non-occupational exposure in Australia.

Study data collection forms were distributed to all prescribers of HIV s100 medications in New South Wales. Basic data collection forms are completed by the prescribing doctor at three time points: at the time of prescribing; at the four-week follow up visit; and at six months following the exposure. Verbal consent of the patient was required for participation. People who fulfilled the criteria to receive PEP but who, after being informed of the risks and potential benefits of treatment, elected not to take it, were also eligible for recruitment.

By the end of 2002, there were 857 participants and 96% (819) received non-occupational PEP. Participants were predominantly men (771, 94.1%) and the median age was 32 years, ranging from 17 to 72 years. A small minority of prescriptions was to individuals who had previously received PEP (80, 9.8%). Of these, 80% (64) were a second prescription for PEP, and one person presented for PEP four times. Around 86% (705) of participants reported a previous history of HIV testing. Baseline HIV testing at the initial consultation was reported in 92.4% (757) of cases.

The great majority of prescriptions (687, 84%) were after male homosexual exposure, and almost all of these exposures involved either receptive (454, 66%) or insertive (210, 31%) anal intercourse. Among the homosexually exposed

participants, 35% reported that their partner was HIV-positive and 60% did not know their partner's HIV status. Heterosexual contact was reported by 47 people (5.7%) and of them, 45% (21) reported contact with source persons known to be HIV infected. Among all sexual exposures for which PEP was prescribed (751), unprotected intercourse was reported by 60% (451), and condom breakage or slippage was reported by 39% (292). There were 11 presentations for PEP resulting from sexual assault: heterosexual assault (4, 36%) or homosexual assault (7, 64%). Of people who had possible exposure to HIV through sexual routes, 118 (16%) reported their sexual partners were casual. The remainder were anonymous (288, 38%).

Of the 64 (7.6%) participants exposed via percutaneous routes, 13 (21%) were injecting drug users who reported sharing of injecting equipment. 49 (79%) were after a non-occupational accidental needle stick injury.

In terms of HIV risk behaviour of the source person, the majority of participants (700, 85.4%) identified their source as a homosexual man (680) or a homosexual man with a history of injecting drug use (20). The majority of remaining participants reported their source as an injecting drug user (51, 6%), a sex worker (10, 1.2%), a person coming from a country with a high HIV prevalence (3, 0.4%). Overall, 287 (35%) participants reported that their source was HIV-positive.

Detailed results of the cohort study will be published elsewhere.

BACKGROUND: QUALITATIVE STUDY

While survey data, such as that summarised above from the quantitative study, provides invaluable data on *who* requests PEP, we need to know about *why* and *under what circumstances* PEP is requested and about the impact of prescribing PEP on behavioural intentions.

The aims of the qualitative arm were to explore in-depth details of risk exposures and to document and analyse the discursive understandings in narratives of men and women who believed themselves to have been exposed to HIV and who sought post-exposure prophylaxis. More specifically, the study sought to explore:

- details of the sexual practices which led to risk exposures;
- participants' knowledge and understandings of risk and safe sex;
- participants' familiarity with HIV, HIV-positive individuals and HIV-related issues;
- participants' awareness and knowledge of post-exposure prophylaxis; and
- the effects of the availability of prophylactic treatment on attitudes towards actual and future sexual practices.

METHOD

RECRUITMENT

At the time of the initial visit, patients were asked if they would like to participate in an interview arm of the study. This report concerns the interview arm of the study only. From March 1999 to July 2001, of the 328 patients who were enrolled in the study, 88 (27%) participated in the interview arm.

DATA COLLECTION

All interviews were conducted by the third author (OH) in a semi-structured, conversational style and typically started with a question eliciting the events leading to an exposure. Participants were asked to describe the event that precipitated the request for PEP in as much detail as possible. In addition, the interviews explored the social and emotional contexts in which exposures had occurred, participants' understanding of safe sex, their experience with HIV and HIV-positive people, their physical and psychological experience of the treatment, and the impact that the availability of PEP may have on their sexual practices in the future. The interviews lasted approximately one hour. They were recorded on audio-tape and transcribed by the interviewer. All identifying information was removed. The de-identified transcripts were then sent to the first and second authors (HK and JE) for analysis.

ANALYSIS

Analysis was informed by Grounded Theory (Glaser & Strauss, 1967), a reflexive inductive method. It was chosen because it allows for the development of conceptual understandings from the data rather than limiting findings to the testing

and confirming of a *priori* assumptions and hypotheses. Because of its openness, there is a space in this method for unexpected findings.

Our analysis involved the identification of recurrent themes, including practices, knowledge, assumptions, experiences and attitudes. The analysis also identified interrelations between themes, including tensions and ambivalences. The interview material was treated as being reflective of certain ways of doing and thinking about un/safe sex. Analysis was not only concerned with the question "what" happened but also "why" and "how".

The report has been written with a view to making the findings of this study available to policy makers and educators to inform policy development, future PEP awareness campaigns and other education activities.

FINDINGS

SUMMARY OF EXPOSURE EVENTS

Of the 88 participants in the qualitative study, two presented with needle injuries and two had come into contact with blood during the course of their work as security personnel at an inner city bar. Of the 84 participants who presented with sexual exposures, five were females who had unprotected vaginal intercourse, and two were heterosexual men who had vaginal intercourse with female sex workers. The remaining 77 were men who had sex with men. Seventy-five of these identified as gay, two did not. There were no injecting drug users among the participants. Two gay men had taken PEP before.

Only a very small number of participants overreacted to the perceived risk and insisted on PEP against medical advice. One woman had some brief vaginal sex without ejaculation with a man whom she had just met at a party. One heterosexual man had touched his penis after he had touched a sex worker's vagina. From both accounts it appears that there may have been other issues at stake for the participants than merely this particular exposure incident. Both stopped treatment after a few days.

By far the majority of participants (95%) presented with exposures due to vaginal or anal intercourse. This involved either sex without condoms or broken/slipped condoms. Just under half of the gay men reported broken or slipped condoms, and of these five said that they had started anal intercourse with a condom and that the partner had removed the condom without their knowledge.

Seven gay men reported oral sex as the reason for requesting PEP. Of these, three reported that the partner had ejaculated in their mouths,

one discovered bite marks and broken skin on his penis, and one reported blood dripping from his partner's penis.

One man had fisted his partner without wearing a glove and discovered broken skin on his arm afterwards, and one man reported that his partner had touched his rectum with semen on his finger after mutual masturbation. One man was not certain whether he had put his penis through a hole in the wall into another man's mouth or his rectum.

Thirteen exposures of gay men happened in serodiscordant relationships, eleven had sex with a casual partner or a friend whom they knew to be positive, and six found out after the event that their partner was positive. The rest were not aware of their partners' serostatus.

For women, the situation was different. However, because of the low number no generalisation can be made. Of the five, three were in serodiscordant relationships, one had sex with a casual partner from a high prevalence country and did not know his status. He tested negative. One woman had sex with a casual partner whom she had just met at a party.

The findings in this report are presented to reflect the sequence of the whole process of "taking post-exposure prophylaxis": Section 1 is concerned with details of exposures leading to PEP: how were risk exposures identified and in what contexts did they occur. Section 2 is concerned with participants' awareness of PEP as an option after an exposure, their sources of information and their knowledge of details of the treatment. Sections 3 and 4 are concerned with experiences during the treatment: clinical interactions and reasons for disclosing PEP to others or not. Section 5 is concerned with the

understandings and attitudes towards sexual practices after PEP and how this experience may affect intent and sexual practices in the future.

One theme which runs like a leitmotif through all the issues discussed in the interviews is that of control: control over sexual practices; control in the post-exposure period; control over decision making processes and disclosure; and taking control in the future.

1 RISK EXPOSURES

This section is concerned with four issues related to risk exposure: 1) the identification and assessment of a risk exposure; 2) the contexts in which exposures occurred; 3) the emotional response to an exposure; and 4) control over sexual practices.

1.1 IDENTIFYING EXPOSURE

The participants in this study, with one exception only, were able to identify and describe in detail the risks that had occurred and to assess them reasonably realistically. Risk identification is a complex issue which involves a variety of strategies and intersects with a number of related issues: 1) control over sexual practices and tension over control; 2) issues of disclosure; and 3) assumptions about a partner's serostatus, including an assessment of one's own sexual practices as well as conclusions about a casual partner's possible serostatus, drawn from his sexual practices.

An exposure was usually identified at the time it occurred. However, there was also some risk identification that was the outcome of conscious reflection on events and practices on the following day.

The Saturday night before I went to the doctor I had unsafe insertive sex with another guy without a condom, and I was worried that I might have contracted HIV doing that. I was worried because I knew it was unsafe. I knew it was a relatively lower risk category of unsafe sex, but I was still worried. [1]

Risk assessment also involves the evaluation of a casual partner's sexual behaviour and drawing conclusions from that behaviour. This includes assessing what certain sexual behaviours and practices may mean in relation to HIV for an individual as well as for the partner, and the possible implications for his serostatus.

Something was troubling me about the whole thing. The fact that he was so kind of light-hearted about it after I'd ejaculated inside him. We hadn't discussed our status. We hadn't talked about it all. I thought, "Well I've done something that's placed me at risk but he's done something riskier than what I had done", I suppose. [51]

Another important factor in identifying a risk was knowing one's own body and its reactions to sexual practice. It was the interaction between knowing one's own body and knowing what constituted a risk which enabled some men to identify and assess risks.

I usually have my wits about me. I always actually have my wits about me as far as the state of my gums, for instance, because I like oral sex. My understanding is that the risks involved in catching it that way are considerably less than other ways, but all the same, if for instance I had a gum inflammation, I would find it very difficult to not be aware of that. [7]

However, risk assessment was not always an unambiguous matter. In some instances there were considerable differences in risk assessment. In the following extract the risk was unprotected insertive anal intercourse by the participant. It was quite brief, there was no ejaculation, and the partner's status was unknown.

I woke up the following day, and I was thinking, and I rang [organisation], and they told me it was still a high risk, and they told me to go to my GP and go on medication. I've been told different things. I did that but then the GP said the chances were quite low, and he said there was still a possibility, and I saw another GP as well, Dr B, and he said, it was quite low risk. I also went to [clinic] and spoke to a counsellor there, and they told me it was high risk. So, I don't know. [59]

Despite the emphasis on rational knowledge and awareness that pervades many of the interviews, there was some tension between knowledge of safe sex practices and actual practice. For example, there were instances of knowing what is safe but doing something that was not, especially when there were emotions involved.

I mean, one thing, it will never happen to you until it happens. That's very true. Even me that I know the high risk. I know everything. I didn't use it [the condom].

Because of love, lust?

Because of passion. [39]

However, there were also instances of the opposite: knowing what is safe but not doing it because fear has turned all sexual practices into a risk.

What do you consider to be unsafe sex?

Everything. I'm pretty neurotic as far as that goes, but I mean, I know intellectually, but I guess emotionally I probably fall into the worried well category. I understand that unsafe sex is in terms of exchange of body fluids, blood but I'm still awkward around saliva, even though I know. I guess I'm a bit neurotic generally. [18]

1.2 CONTEXTS OF EXPOSURE

The focus here is on the physical, social and emotional contexts in which exposures occurred. Here we want to pull the lens back from the sexual encounter and refocus on a person's interaction with their social environment in the context of having sex. The question is: why did people do what they knew to be unsafe or what they thought could be unsafe—what were the contributing factors?

Sexual activity which involves the risk of HIV transmission does not take place in a social vacuum. It involves at least one other person; it happens at certain times; in certain places; it happens before and after other activities, and it can be affected by a variety of experiences. Five themes in relation to context emerged from the interviews: 1) relationship issues; 2) recreational drugs (including alcohol); 3) place; 4) stress; and 5) adventure and rebellion.

Relationships

One important factor in sexual practices leading to HIV exposure was relationship issues: conflict in relationships, the fulfilment of emotional needs in relationships and the effect of these on sexual behaviour. This applied to past relationships, current relationships and possible future relationships.

Past relationships

Experiences and sexual practices in past relationships can affect sexual practices with new partners. For example, after a relationship break-up a gay man might choose to have sex differently with new casual partners and therefore take different degrees of risk.

For me, while I've been in relationships, I actually find being penetrated an incredibly emotional experience, and so having casual encounters in the last six months and going out in the gay scene, I couldn't have casual sex and have somebody cum inside me or want to even enter me. I think that's why women get so involved in a relationship. I mean heterosexual relationships. I think being insertive you can actually detach from it a little bit more. So, up until I met T, nobody's penetrated me except my ex partner who I was with for two and a half years. [17]

Sexual practices and risk-taking strategies with casual partners or with new regular partners can also be affected by a person's previous relationships and how their sexual and emotional needs were met in that relationship. There could then be a deliberate effort to achieve with a new

casual partner what could not be achieved with a previous partner.

Yeah, being receptive was deliberate too, because I found in this five year relationship that I was giving so much and not receiving affection or support, and the upshot of this break-up, I suppose, was realising that. Well, I felt used and taken for granted in this relationship, which was with a very needy person, and it became a co-dependent relationship basically. So, it was important for me to become receptive. I mean, in a lot of ways. There were two reasons. One, that I totally got off in fucking my partner and seeing how much he enjoyed himself, and I guess I sort of felt like I was missing out on that attention that a top can give you. So, I wanted to become the receptive partner to try and achieve that goal. The other reason was, I think, mentally I just couldn't fuck anyone else because he had a special place in that respect. [36]

Present relationships

The quality of current relationships can be an important factor affecting sexual practices. Risk exposure with a casual partner can occur as a result of ongoing problems and tensions between regular partners.

I have a regular partner. We've been together for five years. We'd had an argument and I went for a run and I came back through an area that I knew was a beat and I just ran

into a guy and we had oral sex and he came in my mouth without asking me.

You'd had a row with him?

Yeah, the argument was about monogamy. ... We've been in the process of discussing having an open relationship, and I think P is more keen than I am to have an open relationship. [63]

Me and B we'd been going through a really hard time in our relationship. We work together, we live together, we basically see each other 24 hours a day and our relationship hasn't been good. We've been arguing like continuously. ... That particular day I just kept on drinking and I thought, "Well stuff it. I want to get out of the relationship. I want to be free". ... So I thought, "Stuff it. I'm going to [venue]." I said to him, "I'm going and I'm going to have sex with someone else". [14]

However, risk exposures also happened in the context of a happy and loving relationship with a positive partner. This was reported by both gay men and heterosexual women. In these cases, what is at stake is love, trust and a positive partner's identity as a person.

Well, occasionally, yeah, you think, "Be careful and pull out before you cum", which is probably incredibly stupid, but you do it, particularly when you get to know someone. You start to take calculated risks. You say

to yourself, "Well, S doesn't have any precum". ... And so, you know, as long as he pulls out before he cums, then the risks aren't nil, but minimised. ... He has trouble putting a condom on and keeping an erection and nearly loses it all the time if he puts a condom on. So, you know, if you love someone you take the risk. You calculate the risk. ... Calculating the risk is trusting him, zero viral load. It doesn't mean you're going to take extra risks and start to say, "It's safe to have unsafe sex because you're zero viral load", but I think it must reduce the risk. And you take risks because you love someone. That's what it all boils down to. You take risks because you love them, and you weigh up in your mind the pros and cons and, "Well, I love this person". He gets terribly frustrated by the fact that condoms basically destroy his erection and yet would love to be the active person occasionally. So you think, well, you're willing to take that risk. [10]

Potential future relationships

Sexual practices can also be affected by a person's desire to form a new relationship. This can lead to risk taking when there is some divergence between a person's own needs and wants and the potential new partner's needs and wants. The desire to form a relationship can then override usual practices of having protected sex.

Before I even actually started playing around I asked for the condoms, but he just brought the lube out and I said, "Okay, cool" and I

think after the foreplay and stuff like that I was just carried by it and went along. [25]

The reason for “going along” was given as:

I had this romantic notion, you know, this ideal husband, whatever. So he looked as if, and he actually told me that he'd done all the things he wanted to do sexually and he's ready to settle down, and I'm sort of in that mood. I was really pushing for a relationship to start, and maybe that was one of the reasons why I didn't like to dampen the whole thing by persisting on having safe sex. ... There must have been some signs thrown in there but I just focused on making things work. [25]

Drugs and alcohol

Interviewees reported a broad range of drug and alcohol consumption. The effects of drugs and alcohol at the time of sex that lead to exposure ranged from none at all with strong denial, to small amounts without adverse effects, to large amounts and being seriously affected.

One theme emerging around the consumption of drugs was the assertion of being in control despite feeling seriously affected.

I was putrid ... [I had] at least 15 schooners ... I was drunk but yes, I was in complete control. I knew I wanted to have sex. I went there for the purpose of having sex. ... I remember noticing that he didn't have a condom on. [14]

One man who was so drunk that he actually passed out at a sex-on-premises venue explained:

You were that drunk but you still used condoms and he did too. Then you fell asleep?

I know that I came to probably just after the fellow had inserted.

You seem very sure.

Well, only because just having been fairly sexual for so many years, there's almost that dream-like state that you realise that something is going on and then it takes a few seconds or a little while for it to actually click. You did actually finish having sex with the other person, and this is not a continuum. [61]

Where unprotected sex occurred because of the effects of drugs and alcohol, drugs and alcohol were not seen as an excuse. Rather, what is emphasised in some interviews is the participants' own role in allowing unsafe sex to happen and an insistence that they should have been in control. One man who had unprotected insertive and receptive anal intercourse with three men, who later turned out to be HIV-positive, reported:

What happened was I was at a dinner party on Friday night, the dinner party was friends of mine, and shortly after the dinner party started, some Ecstasy got handed around and we all took some. We were drinking champagne and then there was marijuana. So it very quickly became a pretty out there sort of like party, and it basically degenerated into

something approaching an orgy, or certainly heading in that direction. ... I was really stupid in the way I behaved. I behaved stupidly because of the influence of the drugs, but that's no excuse. I mean, I've still got to be responsible for what I do and if I'm going to take drugs, then I've got to make sure I can look after myself, and obviously that wasn't the case.
[49]

While a causal relationship between alcohol and unprotected sex is acknowledged, this does not mean that participants negate their own responsibility. However, a sense of responsibility and having control can also be in serious competition with desire, and desire can be the stronger force.

Would you have gone home with him if you hadn't been on Ecstasy?

Quite possibly not. I mean, the experience I've had on Ecstasy is that you find people more attractive than you would normally. He's definitely a nice guy. ... He did the wrong thing by me but that doesn't take away from me the responsibility to look after myself. I mean, primarily, it's my decision. I can't blame him for not telling me. I mean it's my decision if I choose to have unprotected sex. ... When I was in bed with S I just completely forgot my commitment to always use condoms. I completely lost touch with that commitment I'd made to myself for some reason. I did what I wanted to do. [6]

Where a causal link between drugs and unprotected sex was acknowledged, it was not necessarily a one-to-one cause-effect relationship. A variety of other factors could be involved.

I was extremely drunk at the time and I very rarely get inebriated but I had that time. ... I had quite a lot, ten drinks maybe. ... Beer mainly and a few Jack Daniels and coke.

Drugs?

No, I can't take drugs because of my schizophrenia. I think he was on drugs though.

Right and then anal sex and I haven't heard the word condom yet?

Well I, because I was understanding, if I thought about it now, I would use a condom even though I don't think it was a high risk thing. Then, I didn't think it was a high risk thing, but even then, I would have used a condom if I'd been sober.

You would?

Oh yeah, but I was so drunk and I really didn't care. I was quite low. I'd just recovered from schizophrenia. I'd just got back on my feet again.
[59]

Place

More risk exposures happened at home with known partners than at sex venues with casual or anonymous partners. Of the 79 sexual risk

exposures, six (8%) happened at beats, 21 (26%) at sex venues, and 46 (58%) happened at home: in serodiscordant relationships, with known casual partners and friends, and with unknown partners who had been met at sex venues.

What is interesting—and we are not sure how to account for this—is that about twice as many exposures happened at a partner’s place than at a participant’s place. The issue of “place” is not one that is explored in the interviews, but we glimpse details about a place as part of men’s account of the exposure. It seems, from the material we have, that it is not the place per se, but a person’s emotional response to being in a certain place, at a certain time, with a certain person which may facilitate certain practices.

In one account, the issue was being unfamiliar with a casual partner’s place and therefore feeling awkward and uncomfortable.

Part of it is that at home I know where the condoms are, the lube. I know where everything is at home. Nothing was visible here. Possibly at the time I could have found it rather awkward asking for it. That has crossed my mind a few times. The non-familiarity of the environment, not seeing anything visible. [16]

Being in another person’s home can provide insights into this person’s lifestyle and their values. People can be seen and interpreted in a certain light through the physical environment they live in, and this interpretation of a person may lead to a willingness to engage in sexual practices which are different from usual practices.

I went to his flat and he doesn’t have much furniture and he works for an airline. I guess there was

something about the fact that he had a very minimalist flat that attracted me. There’s nothing out of place, whereas my flat, there’s things all over the place, and I guess I was kind of intrigued by his lifestyle. ... Yeah, I think it was about the simplicity of the place and certainly about being in someone else’s environment. I don’t think I would have done the same thing in my flat.

If his place had been a mess, do you think you would have made sure the condom was on?

Maybe I would have. There was something certainly about the organisation, the clarity, and the clear cut kind of nature of it. ... Maybe I think it was about, I knew where I was in a way. Maybe it was a feeling of security. Yeah, maybe my defences were down. [51]

Place also played a role in the sense that certain sex-on-premises venues are associated with patrons having a positive HIV status:

[The doctor] said, “It’s one of those places where it’s presumed if you go there you’ve got HIV or you’ve got something. So, if you go there, you run the risk that you may pick something up”. I didn’t even know that those sort of things happen. [14]

Stress

Experiencing stress and trauma could lead to sexual practices which were different from usual safe sex behaviour.

I'd been to a funeral on Friday, a suicide. I didn't know the person but he was a close friend of a close friend of mine. It was a shock to a lot of people. I went with him and the funeral got very, very heavy. ... The partner went into explicit detail of what happened about the suicide. It wasn't very nice. That upset me. [16]

However, the reverse could also be the case. "Time out" from the usual stress could produce positive feelings such as excitement and relaxation, and this, in turn, could lead to a change in sexual practices.

I've been working hard and you're busy doing things, and I think when you're on holidays, you discover part of yourself that you normally forget in some ways. [5]

Adventure and rebellion

One minor theme in the interviews was bravado, tempting fate, rebellion, having a last fling before getting married, and adventure. This was mentioned by some gay men and by one female participant.

I was kind of being very considered about who I was having sex with, and this particular day about a month ago, I was in a more compulsive mood. ... It was a combination of things. A combination of being on my own all

of the weekend and kind of wanting some adventure in my life, and yeah. ... I wanted to be a bit, not bad. I wanted to be adventurous. I wanted to do something that was just spontaneous. I wanted spontaneity, and so I thought I'll ring him up and I'll go and have sex with him. I had no idea he was HIV-positive. ... Yeah, it was very exciting. And for me there's a lot of excitement about having unprotected anal sex as well. That adds to it and that had partly to do with the sort of prohibition against it. Doing something you're not supposed to do and thinking that you can get away with it. [51]

However, in the same interview it is pointed out that these decisions are not taken lightly. There can be considerable tension between following safe sex rules on the one hand and taking control and making one's own decisions, resulting in feelings of guilt.

I actually feel really guilty when I have unprotected sex even if it's in a negotiated situation. There haven't been many times when I've done that, but I feel very guilty because I feel I have an obligation to sort of safe sex culture or something. [51]

1.3 EMOTIONAL REACTIONS TO EXPOSURE

The emotional reactions to an exposure can be characterised in two ways: the kind and the degree of reactions. The two predominant emotions expressed and described were fear and

anger. Both were expressed ranging from a very low degree (“not really worried”) to “a little worried” and “a bit angry” to a high degree (“freaked out”, “mad”).

The emotional reactions to an exposure need to be understood in conjunction with issues of control: losing control over one’s own actions as well as losing control due to a partner’s actions. Emotional reactions also need to be seen in connection with issues of responsibility and disclosure and with risk knowledge and awareness.

Some participants reacted in a very calm and level headed way.

Okay, my feeling is if I become HIV then I become HIV. There is nothing more that I can do about it. I’ve done everything possible apart from not having sex with this person, and to me that’s sort of a mental block if I was to stop having sex with someone because they’re HIV-positive. So, all I can do is live my life how it’s going to present itself to me. [9]

This man was involved in protected receptive anal intercourse with a positive partner and the condom broke. The possibility of taking some control after this event enabled him to accept the possible consequences of this risk exposure.

A similar scenario is presented in the following example. Again, there was protected anal intercourse with a positive partner involved, this time insertive, and the condom broke.

I’m pretty level headed, but I realised that there was a significant or what I assessed to be a significant risk. Whether it was doesn’t really matter because of the emotional effect at the time. I’m pretty level

headed about it. It wasn’t a panic situation but I realised I should do something about it. [12]

Participants with low levels of emotional reactions expressed only fear. This was generally found in situations where the risk exposure was due to a condom breakage or slippage. Men in this scenario had exercised a high degree of control: condom use during sex and prophylaxis after an exposure. In these interviews feelings of anger seem absent.

Anger becomes an issue in interviews where there was some form of unprotected anal intercourse involved. Anger is expressed when there is an unequal balance between a man’s own actions and knowledge about risk and a partner’s actions and knowledge about risk. The following participant had unprotected insertive anal intercourse. His partner told him two days later that he was positive.

I was a little worried. I was a bit angry because he hadn’t told me, but then he told me that he didn’t think it was a risk. That’s why he didn’t tell me. ... He didn’t have much idea of HIV. He just didn’t know what was safe, what wasn’t so safe. He hadn’t seen a doctor for a while. After he was diagnosed he didn’t see a doctor about treatment or whatever. [22]

While this man expressed some anger at this partner, his anger was mitigated by his partner’s beliefs about safe sex at the time and his general lack of HIV-related knowledge.

Anger in relation to control was most strongly expressed where there was some tension over control and risk assessment—that is where there was some conflict between a participant’s own risk assessment and a partner’s risk assessment.

In the following example the risk was unprotected insertive anal intercourse in a serodiscordant relationship. The exposure was described as “it just sort of happened, it just slipped in”.

This is where I'm angry with him because he was playing it down, saying, "It's just not much risk at all. It's the other way round when I'm fucking you. That's where the risk is". I understand there's a lot more high risk there but even then we did it, and then straight afterwards I'm thinking, "Well, hang on, this is high risk. This is quite dangerous". He was trying to tell me it was just like kissing. It's not like fucking kissing at all, it's a lot different from kissing. So, then thinking, "Oh my God, what have I done". [50]

The anger here seems to be not so much about the actual practice but the divergent interpersonal position the two men take in relation to the risk. Anger seems to be much more a response to the partner's down-playing and rejecting the man's concerns about what happened than the actual risk itself.

However, while there could be strong feelings of anger in a situation where there was tension over control, there was also a recognition of mutual responsibility for sexual practice and risk taking. In the following scenario the risk exposure was unprotected vaginal intercourse between a woman and her HIV-positive bisexual male partner. She described herself as “extremely angry” and the reason for her anger was her partner's withholding information about his positive status after he had seroconverted. She was also angry because he had lied to her. He had told her that his bisexuality was a thing of the past despite very recent sexual activities with other men.

The reason I was so mad is because we'd had the discussion [about the partner's bisexual activities] when we decided to move in ... and that was why I was so mad when this happened, because he didn't say that happened two weeks before, which would have given me some opportunity to say, "Right, we need to know and get tested". It was just irresponsible. [8; female]]

However, despite strong feelings of anger and a struggle over control (“You made a decision for me, an almost life altering one”) she acknowledged her own role in her exposure.

I don't really have a good excuse. I mean, I have no excuse really. It was just stupid. [8; female]

1.4 EXPOSURE AND CONTROL

Control in the context of sexual exposure involves physical control over who is allowed to do what to whom as well as taking control verbally after the exposure by initiating a communication process. Participants described control as deciding to use condoms, checking their use-by date, making sure they had been put on properly, checking whether they were on properly on the partner and whether they had stayed on. For some, this was integrated into their sexual repertoire.

I always check the condom whether it's alright, the shelf date.

So you did a few preliminary checks?

Yeah, while I put it on.

You put it on and you're experienced putting it on, as you say with your regular partner you use condoms regularly?

Yes, so I press out the air at the tip and apply some lubrication.

On him as well?

No, he did that for himself.

And did you put some on the condom?

Yeah. So it was perfect from that point of view. I think I put it on the way it should be put on. ... Another thing, I would check every so often whether the condom would be alright still. I don't trust these.

So even in the throws of passion, HIV is always there in your mind?

Yes. It sounds a bit paranoid, but it's not a problem. You change positions and then you go on and on that occasion you can check the condom. [31]

However, taking control was not always a straight-forward and uncontested issue. As sexual encounters involve at least two people, there can be some tension over who gets to exercise control and what happens if there are divergent understandings of risk. This can be particularly problematic in serodiscordant relationships where "risk" and "risk minimisation" can mean different things to different people according to their serostatus and their knowledge and interpretation of clinical markers. In the following example, serostatus was disclosed after sex.

I had sex with him unprotected, and we're still good friends, and he admitted to me that he's positive. I said, "How come we had unsafe sex?" And he said, "But I was taking medication". I said, "That doesn't qualify you to have unsafe sex with me". [53]

Some gay men also raised the issue of controlling whether a partner was allowed to ejaculate inside them. In the first extract, the participant had unprotected insertive and receptive anal intercourse with three men who later turned out to be positive.

Did they cum in you?

No. I would never have allowed that to happen. That didn't happen.

The second extract involved oral sex.

I don't normally allow people to cum in my mouth.

The second form of taking control—that is taking control verbally—typically occurred after a risk exposure. If a person had been exposed to a risk, or perceived to have been exposed to a risk, or was not sure, they initiated a communication process. They discussed the matter with friends, colleagues, a doctor, health services, and a community organisation. In some cases, they chased up a casual partner to find out about his serostatus.

If risk was discussed with a casual partner at all, a partner's assurances that he was negative, that a condom hadn't come off or that he hadn't ejaculated, were not taken at face value. People who take PEP read between the lines. They interpret and evaluate not only what is said by a casual partner but also how it is said and what is

not said. They read non-verbal cues such as hesitation, reluctance and body language. If an answer was vague, such as “I’m okay”, if there were gaps in a partner’s story, or if the story somehow “didn’t fit”, then the participants in this study tended to rely on their own judgements rather than on a partner’s assurances. If a partner showed no concern or no interest in a broken condom, especially when he was receptive or if there was ejaculation, then that usually set off alarm bells, and this was irrespective of age, gender and sexual orientation. The first extract is from an interview with a gay man. There was insertive anal intercourse and the condom broke.

I asked him straight away, “Have you had a test done?” And he very reluctantly answered and said, “Yeah, it’s alright, it’s alright”. And I said, “How long have you had this test done?” And he said, “Oh half a year”. And I said, “Are you sure you were negative then?” And he said “Yes”. But the story didn’t really fit, you know. It wasn’t conclusive. So I didn’t rely on what he said. ... He said he was negative but it came with a delay. If you ask someone a very important question and it comes with delay and someone shrugs his shoulder, it gives you more doubts than security.

Did you interpret the “I’m alright” that he was negative?

Yeah, that’s what he said, but the way he said it made me panic. It wasn’t very convincing. He didn’t show any interest at all, and he was the one a lot more at risk than I was”. [31]

The second extract is from a heterosexual man in his early 20s who had sex with a female sex worker and again the condom broke.

She said, “I get tested every three months”. And I thought to myself, “If the same thing had happened to you, say, yesterday, that’s not going to show up in the results”. It doesn’t mean anything and that’s one of the reasons it didn’t mean anything to me when she gets tested every three months. She said as well, “I’m catholic”. [32]

In one case, the need to take control went beyond sexual practices and post-coital communication and extended into considering legal action.

I even have enough to take him to court, because being in a senior executive position, I operate very well under stress. I automatically got him to sign a full document stating that he was HIV-positive and what had taken place, and that I had access to all his medical records and had it dated and signed and everything else. [4]

Similar to risk identification and assessment (section 1.1), taking control involved seeing, smelling and feeling. Evaluating these perceptions in relation to HIV transmission usually overrode any assurances that a partner gave. What is at stake in the following extract is whether the partner had ejaculated.

When I pulled out¹ he had the condom in his hand and then I investigated myself and put my fingers inside myself and forced out any liquid inside. ... There was a lot inside me because the condom was empty. All it had was maybe just a trace of precum-type thing. That was it, and he'd gone flaccid and still denied that he'd actually cum but I knew he'd cum. ... I told him that he'd cum inside me and that he shouldn't be doing that, and I got really angry and he denied the whole lot but I knew. ... He just kept mentioning that he didn't cum. He said, "There's no risk anyway because I didn't cum". He knew that he'd cum plus I knew what was inside me. The smell and the feel of how much of the juice inside me. So, yeah. [33]

However, despite the strong emphasis on knowledge and control that pervades many of the interviews, there can be tension between knowledge and desire—knowing what is unsafe but following one's feelings at the time and relinquishing control. The following extract is from a man in a three-year relationship with a positive partner.

I think what it was is that we were both feeling extremely horny. He put some lube on me and stuff and then started to sort of lower himself on me and stuff and I'm like: "Hang on a minute". I'm not trying to lay the blame on him because I know I'm

responsible for my own actions and things were feeling really good. So we just did it. ... I think what it was too, we started doing it and it actually felt really good. It's not something I usually do with him and so it was a real turn-on. [50]

In this scenario, taking PEP was an opportunity to restore control.

¹ The participant was receptive and pulled away from his partner.

2 AWARENESS AND KNOWLEDGE OF PEP

2.1 AWARENESS OF PEP AVAILABILITY

Approximately 12 months after the introduction of PEP for non-occupational exposure in New South Wales, a campaign was conducted to promote PEP. One of the objectives was to increase awareness of the availability of PEP. In the post-campaign interviews (January–July 2001), only one participant was not aware that PEP was available (a gay man who explicitly described himself as not attached to the gay community). The others were aware of PEP either from the campaign ads and posters or had heard about it from friends.

In the pre-campaign interviews, participants who were not aware of PEP or who had only some vague recollection that there was “something available” found out about PEP by talking to friends, partners or colleagues, by ringing the hotline, or from a health care provider. In some cases where the risk exposure had occurred with a positive partner, it was the partner who took the initiative by contacting his doctor and making an appointment. This happened in serodiscordant relationships but also with some casual partners.

However, a lack of PEP awareness was not necessarily a barrier. What was important was an extensive social network. This led some participants towards PEP.

I thought, “There’s probably nothing to it”. This was on a Sunday and I spoke to a friend on Monday, who said to ring the Hotline, which I did and they weren’t very sure. They said “Talk to your doctor”, which I did. [5]

Another factor leading towards PEP was a doctor who was not only informed about PEP but also compassionate and supportive.

When did you go to the doctor?

Three hours later. Basically, I called my doctor very distressed. He told me exactly what to do. Told me to get a friend to take me to the beach, calm down while he organises, see if he can get hold of the drugs. He knew about PEP. Basically he actually had the drugs at the time and was able to put me onto the course within a four hour period. It was on a Sunday. So he wasn’t even working. [4]

Some HIV-positive partners were cooperative by providing information about their status, clinical markers and access to their own doctor.

He told me his viral load was not detectable, that he’d assessed that there was no risk, which he had no right to do of course. So I went along with him the next day to his doctor and he was just coincidentally receiving his results from the previous test and his viral load was still not detectable. The doctor we saw was X and I then asked X what options were available to me. He told me about PEP and I thought about it overnight and was back there the next day requesting treatment because it’s obviously a high risk. [6]

However, for some participants awareness of PEP did not necessarily mean that this knowledge came to mind immediately after an exposure. It can take some time for the memory of PEP to be activated, with important implications for timing.

I actually didn't think of PEP until about two days later because I was just scared and worried about it. Then, two days later I remembered and I saw the doctor straight away. That happened on a Monday night about 1.30 in the morning. I remembered [doctor] talking about it but I couldn't remember how long I had to go back and get the treatment. So I went on the Wednesday morning and I thought it was too late but they said to me within 72 hours you were allowed to take it. [48]

2.2 KNOWLEDGE ABOUT PEP

Apart from the two men who had taken PEP previously and those who had had some experience through friends or partners who had taken PEP, participants generally had no detailed knowledge of timing, nature and duration of the treatment. This applied to non-community attached as well as to some gay community attached participants.

I had an idea that PEP existed but I didn't know any of the details. I didn't know of the three-day period after exposure when it's possible to start. I had a vague idea about it. I consider myself well informed on HIV

and safe sex issues really. I read the gay press regularly and I think it's an important thing to publicise. [1]

Timing

Participants had generally no detailed knowledge about the time-frame for PEP. Early presentation was usually due to a sense of panic. Some delay could be caused by consulting friends and sleeping on the event. There was also some risk of delay by waiting for the next available appointment with a doctor and not stating explicitly the purpose of the appointment.

I rang the doctor and made an appointment and saw Y. I couldn't get him the following day. I just made it in the 72 hours.

Did you say what you wanted to see him for?

No I didn't. Yeah I should have. Yeah most doctors around here will drop everything to help. Yeah I know. [64]

The morning-after pill

A common perception of PEP was that of “a morning-after pill”, similar to the treatment available to women to prevent pregnancy. While this is in no way an accurate description of PEP, it does alert people to the urgency of seeking treatment immediately. However, there was also a perception that this term could provide a false sense of security.

It should be called the four-hour after pill really because it would give people a wrong sense of security if

they thought we can sleep over this. That's what I really thought and then after it happened when I contacted my doctor it became evident that it wasn't really the best option. I should have seen him the very day when it happened. [31]

A further misconception associated with the term "morning-after pill" was the number of pills involved and the duration of the treatment. The reality of the treatment regimen could then come as a shock.

Well I was sitting there eating my lunch on that day thinking, "This is very serious, this is what I have to do", thinking I'll ring [clinic] and they'll tell me to go to my doctor and my local doctor is lovely. We've gone there since I was four. And I imagined sitting in his office. It was all very pleasant. And he handed me this big pill and I took it and I went on my merry way. I had no idea. Absolutely no idea. [35]

Even where expectations were less idealistic, they were still far removed from reality.

You said "the morning-after pill". What were your expectations?

I wasn't too sure about it. I thought it'd be like three pills, one a day for three days or something like that. I wasn't aware I was going to be taking seven pills a day for a month. [40]

Side effects

The side effects which participants reported included diarrhoea, nausea, vomiting, rash, depression, cramps, headaches and fatigue. The severity of side effects ranged from none to having to stay in bed. However, most participants who suffered side effects were able to deal with them and to complete treatment. Side effects were described as unpleasant, but were accepted as a trade-off for the possibility of preventing infection.

It was annoying and like I said with diarrhoea and things like that but I had little side effects probably. Maybe other people are affected a lot more. It was an inconvenience but it was necessary. Yeah, I suffered. I'm glad PEP was there. [2]

Neither potential nor actual side effects appear to have factored significantly in participants' decisions to take PEP. Rather, side effects were considered as one part of an equation balancing risk, cost and benefits of the treatment.

I knew PEP was an option but I wanted to understand what sort of risk I had taken. I also knew there were side effects from taking PEP and wanted to weigh up the pros and cons of going ahead with it. Basically risk minimisation. What was the risk to me? How high was that risk and does it balance out the side effect? I decided on balance that I would be foolish not to take it. [67]

3 CLINICAL INTERACTION

Doctors played a vital role in providing detailed information about PEP. Where participants went to see HIV specialist general practitioners, there was generally a high level of satisfaction with the service provided and a feeling that enough information about the medication and side effects had been given. A realistic description by doctors of the likely side effects to be expected did not seem to be a deterrent to take PEP.

He was great. He explained everything and I started the treatment expecting the worst side effects, and it wasn't too bad. [5]

On the contrary, frank and open communication about side effects was appreciated as it helped participants to make an informed decision.

Were you able to take in all the information he gave you?

I think so. We would have spent a good amount, at least a twenty-minute session. I was quite surprised at the amount of time he gave it. He said it was very much my decision and he told me the history of the PEP program and the side effects. He was very honest and I made a conscious decision to go on the program. [75]

Participants were also very aware that PEP was not a miracle cure. They appreciated information about the fact that PEP was still at the trial stage, that it was a prophylactic measure

only and that there was no guarantee that it could prevent infection. This allowed participants to balance possible side effects and potential long-term effects of the treatment against a sense of being pro-active, of taking control, and peace of mind.

He informed me about prophylaxis and some side effects of it and things like that, and said it will be on for one month and he can't guarantee, and I said, "Okay I might as well take some precaution". [53]

I felt I needed to do it to be certain but then at some point along the way I was reading the fine print. It was saying that there was no conclusive evidence what would happen to you in the future, having taken the stuff. [66]

While most participants reported that they understood all the information that was given to them, there was also an expression of need for some written information which could be read at home and in a state of greater physical, mental and emotional calm.

... the hospital gave me drugs for about four days' worth and told me to go to my doctor and he'd give me the rest of the drugs. ... They explained when to take them, the drugs. ... They didn't actually give me any information on paper. I would have liked that. They just told me verbally

when to take them and I had to remember and it was after a big night and I had recreational drugs and stuff. [34]

While doctors played an important role in assessing risks, providing reassurance and support, and providing information about treatment and side effects, participants saw themselves as agents in making the actual decision whether to take PEP or not—a decision informed by medical expertise, but ultimately in the hands of the patients.

The doctor explained what PEP was. She felt I could probably get away with not taking anything. She felt under the circumstances the risk was probably low enough to warrant that but she left the decision to me and I decided to play it safe. [52]

This is also how the doctors in this study saw their own role—to provide information but ultimately the decision was up to the patient.

He [doctor] wanted me to know it was my decision and he mentioned that there was a three percent possibility if he'd [partner] cum inside me and less if he hadn't. I felt there was enough doubt to take the pills. Better to be safe than sorry. [46]

Reactions to treatment in hospital emergency departments were mixed. Criticism included long waiting periods, poor knowledge of staff about PEP, failure to advise about side effects, and failure to offer reassurance and support. While requests for PEP were met by hospitals in all cases,

there was not the reassurance and support that participants expected and that many doctors in private practice offered.

I actually felt that the doctor that saw me that he was not really sympathetic and he sort of didn't really know what he was doing. I mean to handle the case properly. So I had the impression he called the specialist and just got instructions from him, and he just actually gave me the pills and a sort of pamphlet, a print out from the net, information from the net. ... When I spoke to X [HIV specialist] and Y [HIV specialist], they dealt with the situation more reassuring. I didn't get that from the guy I first saw. [25]

However, this was not a universal experience. There were also some very positive comments about the treatment received at public hospitals.

I'm grateful for the PEP and all the support. They were great at [public hospital]. They saw me more or less straight away. I didn't have to wait long. I was dealt with quite quickly and that was great for peace of mind. [28]

I saw the staff there who were great and I took the first dose of indinavir and Combivir that night. I saw A [hospital specialist] after that on the Tuesday night. Found him extremely supportive and always there if I needed to talk to him. [65]

There was also an expression of satisfaction with a public health care system which makes PEP available free of charge.

Not only was I very glad that PEP was available but also how it was made available, and how readily available it was and how readily the health community here in Australia kicked in and got it to me was thoroughly, thoroughly impressive. Coming from the States, I've been in Australia for two years now and I'm part of the Medicare system. The type of care that's generally made available to me has been impressive, the type of care that has been provided to me during this incident by X [hospital] and Y [centre] was thoroughly, thoroughly impressive. I'm very appreciative of that. [58]

4 DISCLOSING PEP

Decisions about disclosing PEP were made by participants in similar ways to other major life decisions—that is in accordance with personal, social and cultural values. This also involved being selective about disclosure.

4.1 REASONS FOR NOT DISCLOSING

Non-disclosure was very much motivated by a desire to control the flow of information to others and the assumptions and judgements that others could make of the person taking PEP, based on this information. For participants who disclosed to no one, there were often several interrelated reasons at stake. They also expressed strong feelings about their motivation for keeping the fact that they were taking PEP to themselves.

Assumptions about serostatus and loss of confidentiality

There were two concerns here. Firstly, there was concern that information about the risk exposure and PEP could be passed on to third parties. Secondly, there was concern that a lack of knowledge about PEP and its purpose could lead some people to assume that someone who takes treatment for prophylactic reasons must be already HIV-positive. It was the fear of this assumption together with a fear of possible breaches of confidentiality which inhibited some participants from telling anybody anything about PEP.

I think the connotations of anything to do with HIV, if you actually tell people you are taking

PEP, I mean it's a prophylaxis at this stage and they could assume you've got it and I think they do judge your behaviour on that as well. [5]

I just didn't want anyone to know. I just didn't want anyone to have that knowledge in case they felt maliciously or otherwise they would tell somebody else and all of a sudden people would think I had HIV. [52]

If the exposure happened in a serodiscordant relationship, it is not only information about oneself that can become the subject of gossip. There were also confidentiality issues related to a positive partner's serostatus.

Have you told anyone you've been on PEP?

No, only my partner. I mean, there's enough weirdos out there and if somebody starts telling them they've got HIV, I think the less people know about it the better.

So you haven't told anyone because of W? W's not telling anyone he's HIV?

He's told a couple of close friends but basically, no. There's too many weirdos out there, and for the same reason that was why I was hiding the pills. [55]

That fears of stigma and breach of confidentiality were not unjustified is illustrated by the following participant. She suffered a needle injury in the course of her work as a cleaner at a hostel and experienced the following reaction from the nursing sister at the hostel.

When I got back from the clinic the word sort of got around when I told people at work that I was given tablets. There was a bit of rumour going around that I must already be HIV-positive, otherwise I wouldn't have been given the medication, and that actually came from our nursing sister. ... She went and told the bosses straight up that I would not have been given that, and I was virtually treated really pretty funny for a few days. ... The next day I heard back that it had already got around that she'd told the managers that I had to be already HIV-positive otherwise I wouldn't have been put on that medication, and it ended up a real bun fight for two or three days until I got the results and I took them back and showed them to the two managers, and they told me to go and see her and show her. [68]

For this woman, breach of confidentiality, assumptions about her serostatus and ensuing stigmatisation were not a mere possibility but actually the reality of her experience.

Embarrassment and fear of judgement

Feelings of shame, embarrassment and stupidity about having been involved in sexual practices requiring PEP were another major barrier to

disclosure. These sentiments were coupled with a fear of social and moral judgements at a time where the outcome of the treatment was still uncertain and stress levels were already high. In that situation, judgemental attitudes by others were perceived as aggravating an already difficult situation: participants were still trying to come to terms with the possibility of becoming HIV-positive.

I was careful not to let anyone see me take the pills. It was partly shame about the whole experience but also I didn't want to have to answer questions about why I was on anti-virals and people think I was HIV-positive. I didn't want to have to explain that I'd had unsafe sex and therefore I was on the PEP program. [1]

In conjunction with feelings of shame and embarrassment, another barrier to disclosure was the fear of being judged as incompetent, irresponsible or morally deficient. The participants in this study were well aware of safe, safer and unsafe sexual practices and they emphasised their commitment to practising safe sex. In this situation, being judged was perceived as unnecessary and patronising.

I suppose I didn't need people telling me about safe sex and blah blah especially when they are the people who are most prone to do it. I know they've had unsafe sex and I didn't want to hear all that ... [79]

Some interviewees actually experienced being judged by close friends who had been told about PEP.

I told my close friends basically. Not all of them, perhaps three or four. I remember a couple of friends judging me and saying, "Oh well, let it be a lesson to you", another saying "I don't judge you" and that friend actually seroconverting during the 28 day period. It was bizarre. We were both going through the same experience. [36]

Judgemental attitudes could also be expected by some participants from their HIV-positive friends.

One of the things is I don't want judgements, but particularly with my friends who are positive. I don't want them to go like not so much, "You should have known better," but, "You're a fool". I don't need that at this moment in time. I can do that myself. There's a defence mechanism there. I don't see the point of telling people before the fact. If it comes back negative, what's the point having them concerned. [16]

Uncertainty

At the time of interview, the participants in this study were still in a state of uncertainty about the outcome of PEP and their final test results. The big question for many was: "What if I'm positive?" It was this uncertainty about the outcome of PEP which constituted another barrier to disclosure.

... if I do or did seroconvert [I wasn't sure] who I want to know or how I would deal with it. I just wasn't sure. [79]

A question of time

The whole PEP experience, from the risk exposure to making the decision, taking the treatment to the final test, was a process which extended over six months. One way of dealing with the impact of the exposure, the treatment regimen, side effects and the uncertainty of the outcome was to wait and see before telling anybody.

I didn't feel that I needed to. It was something that me taking the treatment was a bit of an over-reaction on my part, a bit of over-caution, and I didn't. It's sort of thing I might talk about afterwards and not during. The sort of emotions that go through your mind are the sort you don't necessarily talk about during the course but probably afterwards when you know. Then maybe. [82]

This wait-and-see attitude could also be a strategy to maintain privacy and avoid judgements.

There's too many questions, isn't there, and it's really nobody else's business because I know people will just question my reasoning, ask a lot of questions and at the moment I'm not ready. [8]

Privacy and protection

Privacy and protection from stigma and judgements was one motivating factor for some not to disclose and the decision whether to disclose was dealt with in a similar manner as other major life decisions. If privacy was generally an important issue for participants,

telling others would have placed an additional burden on them.

My belief is it's mine to manage, and I can more easily manage it by keeping it to myself. It's not secretive or dirty but any major thing in my life that's how I approach it. This is a major one, and so I didn't want to spend three, six months of people looking at me and you know, "How are you, oh you've got a cold", and so on. [58]

Fear of stigma and discrimination did not necessarily relate to the actual experience of discrimination but to general societal attitudes towards HIV and AIDS. Fear of stigma could also intersect with a general desire for privacy, irrespective of HIV and PEP.

I think there is still a stigma attached to the HIV issue, and general health I regard as a private matter anyway. [80]

Social and cultural norms

Further barriers to disclosure were social and cultural norms as to what counts as acceptable social behaviour and what can be spoken about. For example, there could be different generational norms and city versus country values.

I remember being quite scared going home for Christmas and I was still on PEP and that was going home to my family in [state] in the country, taking these tablets on the sly.

You didn't tell your family?

No I think because they would have come down very hard on me for it and would not have understood the nuances of living in a city, you know, inner Sydney. [36]

There were also barriers due to different cultural norms in Western culture and in other cultures, which excluded sexual issues from discussion with others outside the family.

Have you told anyone that you've been on PEP?

No, only my brother.

No one else?

No, because in my country, we don't talk about personal things.

Are all your friends from this country?

Yes. [23]

4.2 REASONS FOR DISCLOSING

Compliance with treatment

For people in the workforce, fitting compliance with treatment into their work schedule could be a problem. In this situation, some men disclosed PEP at work. However, this was possible only in an environment of trust and with shared social values, and where the people who were told had some prior knowledge and understanding of the issues at stake when taking HAART.

Closer friends, and I work with a lot of gay people, and you know, for instance I'm working on a job and I'm in the middle of it and suddenly I have to stop. I felt I owed them a reason. So told them. [13]

Raising awareness of PEP

Especially in the pre-campaign interviews, telling others about PEP was an important mode of spreading information about its availability.

I did tell a friend after I'd been on it for two weeks. We've been very close and he had been to [sex venue]. He had sex with somebody without a condom and he was worried and I said, "Well look there is this thing". [52]

However, raising awareness was not always well received, and participants who did this enthusiastically could be treated harshly—one reason why many avoided disclosure.

Yeah, I told everyone. I was so vocal. I just wanted to share that information with other people, just make sure you know if they did have unsafe sex.

What have people's responses been like?

Well, the majority of people was like, "Oh you're so stupid", which I respond to, "I don't want to hear that. I know how stupid I was". [17]

Getting support

For some, telling others about their exposure to HIV and about PEP was motivated by a desire for support, including support in the decision to take PEP.

Told my flat-mate what had happened and I told my best friend. He sort of helped me make a decision too. He's my best friend. I tell him everything, and he came to the same conclusion as me and said, "Do it". I said, "Well it's only a month of discomfort with the tablets. It's better than a lifetime of discomfort". ... And my boss at work, he's very gay friendly. [24]

It could also be a need for support during the four-week treatment period.

It dominated for the four weeks I was on it. I felt I couldn't talk to anybody, any of my friends but I did contact a gay friend and she and her girl friend were my support people for the four weeks. I also told a couple of my other friends. So I had a bit more support. [65]

Support was found to be important especially by participants who experienced strong to severe side effects to the extent where their day-to-day functioning was affected. In this situation, disclosure and the ensuing support made it easier to manage the treatment regimen and side effects.

... luckily I had some great friends at work and they let me have a sob every now and then. ... I'm of the

view that a problem shared is a problem halved and I told four very close friends. [62]

However, disclosure did not always have the desired effect of support, but could actually result in the negative judgements which those who did not disclose feared and wanted to avoid.

I told my close friends basically. Not all of them, perhaps three or four. I remember a couple of friends judging me and saying, "Oh well, let it be a lesson to you". Another saying, "I don't judge you", and that friend actually seroconverted during the 28 day period. It was bizarre. We were both going through the same sort of experience. [36]

By the same token, non-disclosure did not always equate with a lack of support. Some participants mentioned explicitly that not telling others made it easier for them to deal with PEP.

I think it was partly because having come out of a long relationship you don't see people you normally see for a while. I wasn't seeing too many of my old friends and I was making new friends having become single again. I didn't know anyone of the new ones well enough, and as I say, I'm fairly private and I also think I probably felt a little bit stupid and embarrassed. Like I said, I did find it more confronting than I expected, and therefore it was easier for me just to keep it to myself. ... [69]

4.3 BALANCING NEEDS: SELECTIVE DISCLOSURE

Disclosing PEP did not mean telling all and sundry. It was often selective and grounded in a deliberate decision how to best handle the situation. It was also embedded in the participants' social and cultural values, their social networks, their need for support on the one hand and their need for privacy and protection on the other hand.

Criteria for selective disclosure to some but not to others were:

- social closeness (e.g. "best friend" or "close friends");
- a sharing of social values;
- benefit to others;
- familiarity with issues of transmission, treatment and knowledge about HIV in general. The question here was: Can the person told deal with this information or would it "just freak them out" [54].

Where PEP was disclosed selectively, participants mentioned a variety of motivations for and against disclosure and typically distinguished between two quite clearly defined groups of people: those who were told and those who were not. For example, parents were not told to avoid their judgement and to protect them from worrying, but gay friends could be told to raise awareness of PEP.

I only told three people at first. I had no intention of telling anybody else. That's why I didn't go to my parents' place for Christmas. Stayed home because I didn't want to get into a situation, "Why aren't you drinking? Why aren't you doing this?" I did tell this guy when he

spotted my drugs in the kitchen and he asked me about them, and I felt really uneasy about it but I told him anyway. I told him about the new medication PEP. How I was at high risk and my chances were 85 per cent that I was going to be positive and this was a very slim chance that I'd be okay. So, it worked out well. [4]

A regular partner could be told but no one else because of feelings of shame.

Have you told anyone that you've been taking PEP?

No, except for S [partner], but I haven't told anyone else. ... Because it's my business and I do feel like a bit of an idiot for what I've done. I mean, why would you want to advertise the fact that you're on it. I mean, I'm grateful for the program, but it's not something that I particularly want to shout about. I will share it with friends eventually after it's over, but I can't see the point of talking about it. [6]

Some friends were told—and provided support—but others were not, to avoid being judged.

Only a handful of people know. Not many. Only one of my flatmates and a friend in Melbourne who works for a pharmaceutical company and he's been helping me. We've had a few good chats. Had a bad day on Thursday and I phoned him and chatted about that. Initially I wasn't going to tell people.

Why?

One of the things is, I don't want judgements, particularly with my friends who are positive. I don't want them to go like not so much, "You should have known better", but, "You're a fool". I don't need that at this moment in time. I can do that myself. There's a defence mechanism there. I don't see the point of telling people before the fact. If it comes back negative, what's the point having them concerned. [16]

However, there were also more complex negotiations. Non-disclosure to different people was often motivated by different reasons. Participants also balanced their own needs against those of significant others.

I couldn't tell my partner what happened. I did not. I was going to. We have a mutual friend and I spoke to him and my partner's going through a bad time at work and he said, "Might be best not to load this on to him if everything turns our alright".

You told a friend. Did you tell anybody else?

No. I think the connotations of anything to do with HIV if you actually tell people you are taking, I mean it's a prophylaxis at this stage and they could assume you've got it and I think they do judge your behaviour on that as well. [5]

In this case, disclosure to one friend provided support in the decision making process. Non-disclosure to the partner was motivated by protecting him from this problem in addition to his existing problems. Non-disclosure to others was motivated by assumptions which could be made about the man's serostatus and the uncertainty of the outcome of PEP.

Where an exposure happened in a serodiscordant relationship, there was not only protection of a participant's own privacy at stake but also protection of the positive partner—from disclosing his serostatus to others and therefore exposing him to possible stigmatisation.

Did you tell anyone that you were on PEP?

Only B [partner] of course and a friend who saw the tablets lying around.

No one else?

No, and we haven't told anyone that B is HIV.

Why haven't you told anyone about PEP?

Well, for a start, my parents are religious and would see it as a judgement from God. Yeah, and I'd have to tell people that B's HIV-positive and we don't want to do that. Most of our friends are straight and we lost respect from two friends when we told them about B. We don't want that. [19]

5 EFFECTS OF PEP ON FUTURE PRACTICE

The experience of PEP has had two major effects: 1) a shift in attitudes towards others; and 2) an examination of participants' own sexual practices and what the availability of combination therapies might mean for sexual practices in the future.

5.1 COMPASSION FOR HIV AFFECTED INDIVIDUALS AND COMMUNITIES

Compassion for others worked at three levels: at the level of the individual, i.e. positive friends and positive partners in serodiscordant relationships; at the level of PLWHA as a group; and at the level of the communities most associated with HIV/AIDS—gay men and injecting drug users.

At the individual level, in a serodiscordant relationship, taking combination therapies increased the negative partner's understanding of the positive partner's experience of living with HIV—both partners were on a more equal footing.

I don't want to go through a month of taking the pills again. My partner had been on the treatment a month and then I went on treatment. For the first month, if there was an argument, he'd go, "Well, you wouldn't understand this because you're not going through it", and after a month I said, "Well, I do understand it very well". [88]

Having had a risk exposure despite one's best intentions and in conjunction with taking

combination therapy led to a better understanding of the experience of PLWHA as well as less judgmental attitudes towards this group in general.

Taking the pills is a daily reminder that I could be HIV-positive. It's a good experience. I used to be judgemental as I have high standards for myself but the whole experience has taught me not to be so harsh on others and to be more understanding. ... I'm glad that I had to go through it because it's given me an insight into what combination therapies and HIV is like now. It gave me a taste of what you have to go through taking combination therapies. It's not easy or pleasant. [88]

Finally, the experience of combination therapy together with experiencing how easily an exposure to HIV can happen caused in some a major shift in social attitudes towards affected communities and stigmatised groups.

I felt angry but not any more. I used to say that it was gays giving us AIDS but now I realise that's not true. J [doctor] talked to me a lot. I was angry with junkies too, but I agree now with the special injecting room. [15]

What causes these shifts in attitude from judgement to compassion? Firstly, having been exposed to a possible transmission despite high levels of safe sex knowledge, control and long

standing safe sex practices makes people realise that an exposure to the virus can happen to the most conscientious practitioners of safe sex. They realise that there are no absolute guarantees. A risk exposure is no longer an abstract possibility but has become reality.

Another factor is the high level of planning required and the stress involved in sticking to the treatment regimen. People experienced difficulty fitting the pills into lives which are busy with work and social activities. These difficulties were compounded when PEP could not be disclosed for some reason. The most significant factor, however, seems to be the physical and psychological side effects of the drugs and the restrictions that these side effects have on everyday activities.

When I was on those drugs I couldn't do a thing. You get tired really quick. Some days I couldn't get out of bed. I could sleep, I slept ten hours most of the time. I just physically couldn't get out of bed. I was that tired, I didn't want to get out of bed. Emotionally it's pretty hard.
[15]

Despite some rather drastic descriptions of the side effects of combination therapies there was also an awareness that the four-week experience of PEP is quite insignificant in comparison with the ongoing experience of PLWHA.

A lot of my friends are [HIV-positive] and a couple have a problem with taking the treatment all the time and I can sort of see now, and I knew that I had a month but I know they have to take it for the rest of their lives more or less, and that,

yeah, it sort of gave me a little bit of insight as to what they experience.
[64]

5.2 MAINTAINING SAFE SEX PRACTICES

The reactions to the availability of PEP were overwhelmingly positive. At a personal level, participants were glad and grateful that PEP existed. PEP gave them hope, relief and put the mind at ease. PEP was described as “a comforting bridge” and “light at the end of the tunnel”. It reduced anxiety and stress while waiting for test results and enabled participants to carry on with their lives. However, despite these positive reactions, PEP was not seen as a *carte blanche* for unprotected sex. Rather, on balance, PEP was seen as the lesser of two evils, both in the short term (“Six weeks of anxiety waiting for the results would have been worse”) and in the long term (“I’d rather be sick for four weeks than for the rest of my life”).

One strong theme running through the interviews was a determination to either maintain existing high levels of safe sex or to increase safe sex practices in those cases where PEP was perceived as a wake-up call. This determination was motivated by three factors: 1) the experience of combination therapies; 2) the uncertainty of biomedical knowledge; and 3) reflection on a potentially HIV-positive future.

Experience of combination therapies

The experience of a four-week course of combination therapies for prophylaxis and the difficulties in adhering to the treatment regimen strengthened participants’ determination to avoid risk exposures in the future.

How do you feel about the whole thing now?

Well I would say it's not going to make me less safe in the future, drug affected or not. I don't want to have to put myself through that ... having to take the pills regimented and the worry and the stress that it all causes. I mean, I would rather not have to do that. ...

Are you still as worried even though PEP is available if you have another risk?

I would say there is no way I would want to keep running back to my doctor to get drugs. [52]

While HIV is no longer seen as an immediately life-threatening disease, it is still a disease one would rather not have. What is at stake here since the availability of treatments is quality of life.

Do you feel being HIV is less terrible say than five years ago or something because of the treatments? It's hard to phrase this but...

I know what you're getting at because I had this discussion with a friend recently. I was surprised when a friend of mine said he wouldn't be as worried as he was before. I suppose, my outlook, if I ever contracted HIV, it would be different because of the treatments available, and I know people who have been HIV-positive for like fourteen years are still living relatively normal lives. So, in that respect, my opinion has changed, but I still think you should

be safe. It still is something I wouldn't ever want to get. I wouldn't put myself at risk because you don't know how long and there are different risks.

You realise you would have to take these drugs all the time?

Yeah, I was thinking, "Oh my God, I hope I never become positive because there's no way I want to take these drugs for the rest of my life". [57]

HIV is measured against two time scales: the history of the disease and the repositioning of HIV from a disease leading to death to a chronic illness. On the scale of an individual's life span, a future of living with HIV is measured against the present without HIV. What is at stake here, then, is a change from no illness to living with a chronic illness, and this change, participants felt, could be controlled and avoided.

In those cases where the availability of HIV treatments may have reduced the fear of becoming HIV-positive and may have made safe sex less important, there were clear "before" and "after" perceptions.

Before my taking PEP I always had this notion, and I knew that it was wrong, but I had this notion that if ever, like when I go cruising around the gay beats here and there were a couple of times where I actually just saw this handsome guy and I just like went with him and he didn't wear condoms, I said, "okay". I had this thing in my mind that if I do get the bug, it's not like a death sentence any more. So, may be I'll lead a normal

life. I know my options would be limited but not as bad as may be if I had contracted it five or ten years ago. So, all the while I was thinking, "If ever I do catch it, there's drugs there that will help me". But after PEP I know how difficult it is to take the drugs. [25]

Experiencing side effects, however, was only one factor in the decision to practise safe sex in the future. For participants who had experienced no side effects, this did not equate with a perception that PEP could be a substitute for safe sex. There was still a determination to avoid a repetition of PEP.

I'm still very careful. Probably even more careful because even though PEP is there and though it's only for a month, it could have side effects. Because I was lucky not to have side effects that doesn't mean that I can have unsafe sex and then have treatment any time I want. That's not what I want. It's made me, influenced me to be more careful. [71]

The limitations of biomedical knowledge

While participants were grateful for the availability of PEP and the sense of control and peace of mind it provided, there was also a strong awareness that PEP was not a guarantee for a negative serostatus at completion of treatment. There was a strong awareness that PEP is still at the trial stage and that its effectiveness has not yet been proven. There was also an awareness that treatments work to a certain extent but that they are not a cure for HIV.

Another deterrent was the toxicity of the drugs, and while treatment may provide benefits in the short term, these are off-set by long term problems.

I think the treatments are fantastic but I also think it must be a massive assault on your kidneys and everything else. [64]

I know that the chemicals can be pretty toxic and I'm conscious of the fact that the pills are not doing wonders for my body. So, I'd rather avoid the whole thing. [12]

For some participants in the study a "wake up" experience happened when they were confronted with the reality that PEP was not "a morning-after pill" but several pills to be taken several times a day over a four-week period. The number of drugs, the extent of time in conjunction with compliance difficulties and side effects were seen as a deterrent to sexual risk taking.

Knowing that PEP is available, would it make you take risks?

No, probably the opposite. It sort of gives you a taste of what it would be like to be HIV-positive and have to take those drugs continuously and it was in my mind that it was a one-off tablet that you could take and all would be fine. When I actually realised when I went to the pharmacy and I had three big bottles of tablets that I had to get through and the way they make you feel, it makes you think twice about doing anything risky. [84]

An opportunity for reflection

Taking PEP was an opportunity to reflect on the broader ramifications of HIV. It was an opportunity to reflect on sexual practices in the larger context of life, of one's own future and on the impact HIV infection would have on significant others. Especially for young people, there was a balancing of sexual risk taking and sexual pleasure against their plans for the future and what a possible infection might mean for this future.

I think it was actually the best thing that could ever happen. I don't know how you could think that because it was quite traumatic. But it made me start to look at myself and made me take responsibility for my life and made me realise, it's almost like being hit by a car. You get a second chance in life and you start looking at things differently and my focus is just fully on what I have instead of what I could have had. [43]

Closely related with the impact of a possible HIV infection on one's own future was the impact such an infection would have on significant others. What is at stake here is a balancing of different kinds of risk: sexual risks versus social risks of losing out on opportunities and on relationships. This was reported across the spectrum by gay and straight, male and female participants.

... it's made me very aware and I'll definitely not go back in that sort of area with a sex worker again. No, it's just too risky. There's a lot of things I want to do with my life and I can't

afford, I don't want to risk that. It would kill my parents. [32; heterosexual man]

I was thinking during the weeks waiting, I was thinking, "Gosh, what if I am HIV?" I was thinking of my mother and the rest of my family and friends. I thought, "No, I don't want to be HIV. I want to have children and we might break up and I'm HIV. I'm still stuck with that and I don't want to". So I made the decision not to be unsafe again. ... I want to get married, have children. [56; female]

Would you do the same thing again if the same situation arose?

Oh, certainly, but I don't think I'd put myself in a situation now. ... I think going through PEP, it sort of puts things into perspective and you realise it's not worth it. There's a lot of other things in life which are so much more important and, yeah, it becomes more important afterwards ... your relationship, your health, your life and your friends and family and everybody because what you do and how it affects you affects them as well. [5; gay man]

In these contexts, taking PEP was an opportunity to reassess priorities. For these men and women the stress of taking PEP, the possibility of seroconverting and the stress on existing and possible future relationships weighed more heavily than the physical pleasure of unprotected intercourse.

For some, going through the process of risk identification, risk assessment, taking the pills, testing and waiting for the results was a learning experience. Especially for young gay men who have not had much experience with HIV and HIV-positive people, this was an opportunity to learn about HIV and about treatments.

How do you feel about the whole experience?

I'm actually sort of glad in a way because I'm a lot more responsible when I have sex now, whereas before I wasn't because I didn't know anybody who had HIV. So, I just sort of wasn't worried about it until this happened. I sort of realised that it's a real thing, something to worry about. ... I've realised now how stupid it is. At the time I didn't really think about it. I always heard or read about HIV and all that stuff, but I didn't really pay much attention to it. [22]

For older, more experienced gay men taking PEP was an opportunity to critically engage with their interpretations of safe sex messages and their interpretations of risk and to evaluate these in relation to risk assessment by professionals.

Is the safe sex message as strong as ever?

Very strong. I think it should be even stronger. The message I got was that I always believed that insertive—the active partner is virtually hardly any risk. ... I was initially going to forget about it and I was quite surprised when I saw my doctor and he said that the risk, although very small, it's there. I think

subconsciously, when the message is given, you accept the message, but subconsciously you twist it in a way to suit your needs. I think if the message was saying something like: "Active partners are also at risk". The message comes over like the passive partners are at more risk, and you draw another conclusion: "If I'm active, I'm fine". [5]

The experience of PEP could also reinforce the need to actively take control over sexual practices.

What I've learned from this is that I need to take more control in making sure that everything's in place rather than relying on other people to do the right thing. [62]

5.3 TENSIONS AND AMBIVALENCES

However, despite the determination to practise safe sex in the future there were tensions and ambivalences in the gay men's narratives. These can be summarised as 1) safe sex versus desire; 2) no absolute guarantees; and 3) balancing of multiple possibilities.

Safe sex versus desire

This duality has already been discussed earlier, where men described desire as one factor leading to a risk exposure. In this section the discussion is concerned with the tension between safe sex and desire in relation to sexual practice after PEP. This seems to be particularly salient in the narratives of older gay men—men who have

experienced the impact of the epidemic, who reported having practised safe sex since the beginning of the epidemic and who have been involved with the gay community.

Are you tired of safe sex?

I am, yes, I'm sick and tired of safe sex practices. I'm part of the community. It's been pounded in my head, safe sex or death. I was part of the, you know, the very early 80s when they put it together. I was the target community of the message, you know, unsafe sex equalled death, and it was pounded in your heads, and as I said earlier, thank god. I think I'm alive because of that message being delivered to me, and because of my adherence to that message and belief in that message. Yeah, I am tired of safe sex practices. I fantasise quite a bit what unsafe sex would be like. It's become a kind of common topic with people my age. [58]

In this situation of tension between two strong forces either side can win. In the previous example protected sex won over desire: the condom was on and the risk exposure was due to a broken condom. In the following example, the condom lost the battle.

I mean, it will never happen to you until it happens. That's very true. Even me that I know the high risk. I know everything. I didn't use a condom.

Because of love, lust?

Because of passion. [39]

A similar tension can be seen between safe sex knowledge, a perceived obligation to “adhere to safe sex culture”, and the excitement to act against this obligation.

It was very exciting, and for me there's a lot of excitement about having unprotected anal sex. That adds to it and that has partly to do with the sort of prohibition against it. Doing something you're not supposed to do and thinking that you can get away with it. [51]

While for many men the safe sex message was still strong, in the kind of tension described here safe sex messages have not produced the desired effect. On the contrary, for some they may actually have become counter-productive.

No absolute guarantees

One theme which runs through many of the gay men's narratives is that a risk exposure happened *in spite of* their knowledge of safe sex and their insistence on protected sex. What is acknowledged here is that there is no absolute, one-hundred per cent guarantee for safety. Accidents can and do happen and “unsafe” sex is not necessarily an indication of irresponsible behaviour.

Are you glad that PEP was available?

Oh god, yeah, absolutely. It's a facility worth having around if it helps. God, yeah. I mean, accidents happen. You don't have to be irresponsible for accidents to happen. You can be responsible and they still can happen. [88]

Accidents can, roughly, be grouped into two categories: accidents where safe sex technology—i.e. condoms—failed despite efforts to handle this technology correctly when putting a condom on oneself.

I think I couldn't have been more careful than this time when it happened. I would never allow someone to put a condom on me. I would always do that myself. I would press the air bubble out. I would put some lube on my penis, a tiny little bit, not much so it doesn't slide off, and I would not allow oral sex to happen because teeth can damage a condom. [31]

And when putting it on a partner.

I put the condom on him. I always insist on doing it myself so that I can inspect the condom myself. Maybe it's an insecurity complex. I don't know. I've always done that because that way I get to see if it's faulty, if it's got a tear, a rip or anything. It's my life that's at risk. [38]

The second kind of accidents were those where human behaviour “failed” in the sense that behaviour, despite all efforts and despite the best intentions, does not always conform with prescribed norms. One man in a serodiscordant relationship said:

It's about: I can do what I can do and try to do my best to avoid it, but I'm not going to live my life wrapped in plastic. I don't mean wearing

condoms, but I mean I'm not going to live a bubble. I guess my spirituality comes into it. I do what I can do to avoid it and I do my best, and occasionally we're all human. We slip up but I don't ever take risks. [72]

Another man asserted:

I've had safe sex for fifteen years and it still happened to me [insertive unprotected anal intercourse].

Yet another man has had safe sex for seventeen years with two risks in these seventeen years. He had very clear ideas about his own sexual practices and what he allows others to do to him.

My sexual practices are: I won't let people ejaculate over me and I won't swallow if I have oral sex. I will not brush my teeth if I know I am going to the beat because I don't want any cuts or ulcers. I never let anyone ejaculate ever. [24]

Despite these tight measures of control, he was exposed through a slipped condom.

Balancing possibilities

In the previous section we discussed PEP as an opportunity to reflect on broader ramifications that a potential HIV infection may have on participants' own future and on significant others. In that context the fear of infection tipped the balance clearly towards maintaining safe sex practices. However, in this balancing act a lack of fear did not necessarily translate into more risk taking, rather the contrary.

I used to be pretty worried about getting HIV, like the month after I had the cumming-in-mouth incident. I was really worried. I was so worried that I got stress nausea, and that was about a month until I had the test and I was negative. But now, after I've known about the treatment, and some of my friends are HIV-positive and leading fairly normal lives, I think now I'm not really worried. If I did seroconvert, I wouldn't be devastated. I'm not as worried in some ways as I was before, but by the same token, I've become safer. It's maybe a contradiction. [33]

Another apparent tension was that between admitting to possible risk-taking in the future because PEP is available for sexual exposures and at the same time reassessing perceptions of past risk taking.

How do you feel about it all now, about the whole experience?

In a way I feel like as though I've been given a bit of a green light to have unprotected insertive sex, to be honest about it. ... Well, I guess I'm not as worried in terms of insertive, like I said. I'd say, now in the same circumstances, if I was feeling the same way, I think I'd probably do the same thing again, but hopefully, going through the experiences, I don't know if I'm saying two different things here. Hopefully, going through the experience has told me that it's not worth the trouble. By the same token, I don't feel I'm putting myself as much at risk as I originally thought. [51]

What is at stake in this context are not just "objective" assessments based on statistics but also an individual's perceptions of risk and what this might mean for the future and in relation to PEP.

Two further factors which were balanced in relation to treatment availability and risk-taking in the future were an individual's own (negative) experience of the physical and psychological effects of PEP and their (positive) experience with HIV-positive people who live satisfied and fulfilled lives.

I think I'm less worried. Having lived for ten years with being worried about it, it's like well there are other things to think about in life.

Are you desensitised to HIV?

I wouldn't say that I was desensitised because I'm around it all the time. I have people around me who are HIV-positive, but I'd say I'm less struck by fear. I see people living with HIV more now. So, I guess I'm not as fearful. The fear for me ten years ago was caught up with the stigma and the illness and the debilitation and the wasting away. [51]

Balancing safe sex practices against the availability of treatments was also described as a continuum, not as an either/or choice, especially in serodiscordant relationships. Sexual practices were understood in conjunction with a positive partner's clinical markers and framed as an ongoing process of negotiating and balancing possible alternatives. In the following example, the couple uses condoms. They had two breakages and subsequent PEP.

Do you think you'll be able to sustain your safe sex behaviour?

It gets harder and harder as time goes on. It gets harder and harder after two episodes where you found that basically you've had a scare and nothing's happened. You do start to get blasé and start to think in the back of your mind, "Oh, S's viral load is nil, is zero, and the chances of me getting it from him are probably close to the same". Then you think, "No, you're being stupid". Having two scares like this instead of making it easier, in a lot of ways it's making it harder. [10]

DISCUSSION

PEP for sexual exposure involves much more than unprotected intercourse and a four-week course of antiretroviral drugs. It entails admitting mistakes, failure, bad luck, losing control, disappointment for letting one's standards drop, acting in spite of one's better knowledge and dealing with emotions of anger and anxiety. Taking PEP also includes sourcing information in a situation of stress, negotiating the health care system, often outside of normal business hours, and making decisions about treatment and disclosure. And finally, taking PEP means reflecting on possibilities for the future.

All aspects of PEP—the exposure itself, making decisions about treatment and disclosure, dealing with side effects and decisions about sexual practices in the future—are firmly grounded in the contexts of people's lives, their values, and the social and cultural norms of the communities to which they belong.

There is a strong resonance in these narratives with the public health discourse of knowledge, rationality and control (Bakhtin, 1986, Rosengarten et al., 2000). People who take PEP are generally well aware of safe sex messages based on condoms and a water-based lubricant. Similar to Rosengarten et al. (2000), participants in this study emphasised their general use of condoms and their knowledge and skills in handling this technology. They were also aware of degrees of safety. If they were not, they were determined to acquire this knowledge.

There is strong resonance with rationality. This pervades various aspects of the PEP experience: rational decision-making and reasoning about sexual practices, about taking treatment, about disclosure and about intentions for the future. However, abstract ideals of rationality and control

were confounded by the somewhat messy reality of the physical, social and emotional contexts in which exposures occurred.

Relationships in general are complex, and the casual relationships of gay men have a high degree of complexity of partner types and circumstances (Prestage et al., 2001). The narratives in this study reveal a further layer of complexity to sexual relationships in addition to partner type: the social, emotional and spatial contexts in which risk exposures can occur, in spite of safe sex knowledge and rational decision making.

One important factor in sexual practices leading to HIV exposure seems to be relationship issues: ongoing conflict in regular relationships, vulnerability after relationship break-ups and the uncertainty of new relationships. One particularly vulnerable group is gay men who have just ended long-term monogamous relationship. They are vulnerable in two ways. There is the emotional damage and the ensuing sense of loss from the break-up itself. In addition to that, there is the difficulty of re-entering the scene and having to negotiate sexual practices with new casual partners, and this negotiation is not always successful.

A group which needs special consideration is serodiscordant couples. In serodiscordant relationships clinical markers are factored into sexual practices and into risk assessment after an exposure. Similar to Rosengarten et al. (2000), there is no simple causal relationship in this study between clinical markers and unprotected anal intercourse (UAI) but there is an interrelation between a range of factors, including different knowledges and attitudes. These differences can result in tensions over risk assessment and

control—both partners claim the right to make their own decisions over practices and risks based on their respective knowledges. For positive men, infectivity and risk assessment are based on their knowledge of clinical markers, where undetectable viral load means reduced infectivity. For negative men, risk assessment is based on the public health message of using a condom. In this study, nobody relied on the possibility of reduced infectivity of a positive partner with undetectable viral load. All decided to take prophylaxis.

However, knowledge is not a monolithic, uncontested entity. When it comes to negotiating sexual practices and condom use, there can be multiple understandings of the concept of “shared responsibility”, where both partners are responsible for safe sex practices. For a positive man it can mean taking the receptive position in UAI with a negative partner. For a negative man it can mean disclosure of serostatus and/or using a condom. This can result in conflict and tension over control when a positive man discloses his serostatus after UAI has occurred.

There is also some evidence in these interviews that HIV prevention messages such as “assume every partner is positive” are read differently by positive and negative men and can result in different assumptions and practices. For a negative man it may translate into “assume a partner is negative if he does not request a condom.” For a positive man it may translate into “assume a partner is positive if he does not request a condom”. Messages are interpreted according to the knowledge we bring to a message, and in relation to PEP, these messages are interpreted in convergence with a man’s own serostatus. If a partner does not request a condom, he can be assumed to have the same serostatus.

The narratives also strongly resonate with the discourse of control. Control is exercised in various forms and permeates all aspects of PEP. Physical control determines what participants do

sexually and what they allow others to do to them. Verbal control takes place after an exposure when they question their partners about practices and serostatus, when they seek information about prophylaxis possibilities from friends, doctors and community organisations. Control over decision making processes allows participants to decide whether to take the treatment that is offered to them, whether to disclose the incident and to whom. Control over sexual practices becomes an issue again in the determination of participants to practise safe sex in the future after the experience of PEP.

There is also a strong emphasis on being in control despite the influence of legal and illegal drugs. However, as the sexual practices leading to PEP involve at least one other person, control over sexual practices can be contested, it can break down, and it can be deliberately relinquished. What caused the need for PEP in these narratives is a temporary absence of control, not a lack of it. In the aftermath of these complex social and emotional processes, PEP becomes a means to restore order, to reclaim control: making decisions about treatment, about disclosure and about safe sexual practices in the future.

A temporary loss or the relinquishing of control during sex is compensated for immediately after the act. Even though awareness of PEP in the pre-campaign interviews (March 1999—January 2001) was low, for the participants in this study this was not a reason for inactivity. Participants actively sought information about the level of risk to which they had been exposed and about possibilities “to do something”. An important factor here is social connectedness, or social capital² (Bourdieu, 1986, Putnam, 2000). Participants had social connections they could mobilise in their search for information: partners,

² Social capital refers to the networks of social relations and social connections which have value for individuals as well as for groups.

friends, colleagues, siblings, doctors and community organisations. If information could not be obtained from the first point of contact, it could snowball from there, with various contacts drawing on their respective social networks. This quest for information was a first step in restoring control.

The public health discourse of rationality and control is also clearly discernible in the decision-making process about taking PEP. This process followed a cost-benefit model, where the short-term costs of the treatment—restrictions, side effects and reduced quality of life—were balanced against the long-term benefits of preventing HIV infection. Infection was considered to be the “higher price” to be paid, in spite of the availability of HIV treatments. The short-term costs were also a factor in participants’ decision to avoid risk taking and another round of PEP in the future.

An element of control was also present in the interactions with doctors prescribing PEP. Medical expertise provided information about levels of risk, available options and possible consequences of the drugs. However, the decision to take PEP was taken and owned by the individual.

Control was also an important issue in disclosure. In counselling work, disclosure is generally seen as positive and healthy. However, HIV is still associated with prejudice, stigma and discrimination. In this context, disclosure may actually be unsafe and the fear of being an outcast is very real (Worth et al., 2001). While non-disclosure of PEP means that people who take PEP are without support during the treatment, it also means privacy and protection from harm. Moreover, as has been argued by Rosengarten et al. (2000), after twenty years of safe sex messages emphasising condoms, “not to use a condom as a negative man, after being told so many times,

is to lapse” (Rosengarten et al., 2000, p. 32). Simply the fact of having had “unsafe” sex without a condom can be a cause for judgement from others.

There are different issues at stake for older and younger gay men with implications for prevention messages. Different experiences of the epidemic, different sexual histories in parallel with the change of HIV/AIDS from a deadly disease to a chronic illness, different experiences with HIV-positive people and different expectations for the future are related to different perceptions of risk and different attitudes towards a possible seroconversion and a life with HIV. Prevention messages need to take these differences into account to produce the desired effect.

The conclusions about intentions for sexual practices in the future which can be drawn from this study resonate with findings from surveys in Australia and in the US. In this study, PEP is perceived by those who had it in the way it was intended by health authorities: as a means to reduce the risk of infection when other risk reduction strategies had not worked. It is understood and used as a means of damage control, an emergency brake that can be pulled when the normal brakes have failed (Waldo et al., 2000). This attitude is also reflected in the most recent Sydney Gay Community Periodic Survey (Hull et al., 2003). This survey showed continuing strong disagreement with statements that new treatments in general and PEP in particular have made safe sex less important. While it is not possible to make predictions for future behaviour from these narratives, follow-up survey studies in the U.S. found that PEP had no effect on increased risk taking in those who had been given PEP after a sexual exposure (van der Straten et al., 2000, Martin et al., 2001).

What cannot be evaluated at this stage is the effect of time. The interviews were conducted

at a time when participants were still uncertain about the outcome of PEP. They had all had the baseline test, some were still on treatment, some had had their three-month test but all were still waiting for the six-month test and the final result. The experience of exposure, shock, fear and side effects was still quite fresh in their minds. Whether the good intentions will actually translate into practice in the future is still open and would have to be investigated through a follow-up study.

CONCLUSION

PEP in this Sydney-based study is understood and used in the way and for the purpose it was intended: as a risk reduction strategy when other strategies have failed. After a temporary loss of control over safe sex practices, PEP is perceived as a means to restore order and to reclaim control. However, a follow-up study is needed to investigate the effect of PEP on future sexual practices of those who have taken PEP. While there were no seroconversions in this study, the effectiveness of PEP is not yet proven. Nonetheless, the availability of PEP is a source for hope and the restoration of order after an exposure. Future prevention messages should take into account the different experiences and expectations of older and younger gay men and should also address the social and emotional contexts in which exposure to HIV can occur.

REFERENCES

- Bakhtin, M. (1986). The problem of speech genres. In C. Emerson & M. Holquist (Eds.), *Speech genres and other late essays*. (V. W. McGee Trans.) (pp. 60–102). Austin: University of Texas Press.
- Bernasconi, E., Jost, J., Ledergerber, B., Hirschel, B., Francioli, P. & Sudre, P. (2001). Antiretroviral prophylaxis for community exposure to human immunodeficiency virus in Switzerland, 1997–2000. *Swiss Medical Weekly*, 131, 433–437.
- Bourdieu, P. (1986). The forms of capital. In J. G. Richardson (Ed.), *Handbook of theory and research for the sociology of education* (pp. 241–258). Westport, Connecticut: Greenwood Press.
- Cardo, D. M., Culver, D. H., Ciesielski, C. A., Srivastata, P. U., Marcus, R., Abiteboul, D., Heppenstall, J., Ippolito, G., Lot, F., McKibben, P. S. & Bell, D. M. (1997). A case-control study of HIV seroconversion in health care workers after percutaneous exposure. *New England Journal of Medicine*, 337, 1485–1490.
- Centers for Disease Control and Prevention. (1998). Management of possible sexual, injecting-drug-use, or other nonoccupational exposure to HIV, including considerations related to antiretroviral therapy. *Morbidity and Mortality Weekly Report*, 47(RR17), 1–14.
- Centres for Disease Control and Prevention (2001). Updated US public health service guidelines for the management of occupational exposures to HBV, HCV and HIV and recommendations for post-exposure prophylaxis. *Morbidity and Mortality Weekly Report*, 50(RR11), 1–42.
- Glaser, B. G. & Strauss, A. L. (1967). *The discovery of grounded theory: Strategies for qualitative research*. Chicago: Aldine.
- Guay, L. A., Musoke, P., Fleming, T., Bagenda, D., Allen, M., Nakabiito, C., Sherman, J., Bakaki, P., Ducar, C., Deseyve, M., Emel, L., Mirochnik, M., Fowler, M. G., Mofenson, L., Miotti, P., Dransfield, K., Bray, D., Mmiro, F. & Jackson, J. (1999). Intrapartum and neonatal single-dose nevirapine compared with zidovudine for prevention of mother-to-child transmission of HIV-1 in Kampala, Uganda: HIVNET 012 randomised trial. *Lancet*, 354, 795–802.
- Hull, P., Van de Ven, P., Prestage, G., Rawstorne, P., Grulich, A., Crawford, J., Kippax, S., Madeddu, D., McGuigan, D. & Nicholas, A. (2003) *Gay community periodic survey: Sydney 1996–2002* (Monograph 2/2003). Sydney: National Centre in HIV Social Research, University of New South Wales.
- Kahn, J. O., Martin, J. N., Roland, M. E., Bamberger, J. D., Chesney, M., Chambers, D., Franes, K., Coates, T. J. & Katz, M. H. (2001). Feasibility of postexposure prophylaxis (PEP) against human immunodeficiency virus infection after sexual or injecting drug use exposure: The San Francisco PEP study. *Journal of Infectious Diseases*, 183, 707–714.
- Martin, J. N., Roland, M. E., Bamberger, J. D., Chesney, M. A., Kahn, J. O., Coates, T. J. & Katz, M. H. (2000). *Post-exposure prophylaxis for sexual exposure to HIV does not lead to increases in high risk behaviour: The San Francisco PEP project*. Presentation at the 8th Conference on Retroviruses and Opportunistic Infections. Retrieved on 6/9/2002 from <http://www.retroconference.org/2001/abstracts/abstracts/abstract/224.htm>

- NSW Health Department (1998). *Management of non-occupational exposure to blood borne and sexually transmissible diseases* (Circular no 98/106). Sydney: NSW Health Department.
- Prestage, G., Van de Ven, P., Grulich, A., Kippax, S., McInnes, D. & Hendry, O. (2001). Gay men's casual sex encounters: Discussing HIV and using condoms. *AIDS Care*, 13, 277–284.
- Putnam, R. D. (2000). *Bowling alone: The collapse and revival of American community*. New York: Simon & Schuster.
- Rosengarten, M., Race, K. & Kippax, S. (2000). *“Touch wood, everything will be ok”: Gay men's understandings of clinical markers in sexual practice* (Monograph 7/2000). Sydney: National Centre in HIV Social Research, University of New South Wales.
- Tsai, C. C., Follis, K. E., Sabo, A., Beck, T. W., Grant, R. F., Bischofberger, N., Benveniste, R. & Black, R. (1995). Prevention of SIV infection in macaques by (R)-9-(2-phosphonmethylmethoxypropyl)adenine, *Science*, 270, 1197–1199.
- van der Straten, A., Gómes, C. A., Saul, J., Quan, J. & Padian, N. (2000). Sexual risk behaviors among heterosexual HIV serodiscordant couples in the era of post-exposure prevention and viral suppression therapy. *AIDS*, 14, F47–F54.
- Waldo, C. R., Stall, R. D. & Coates, T. J. (2000). Is offering post-exposure prevention for sexual exposures to HIV related to sexual risk behavior in gay men? *AIDS*, 14, 1035–1039.
- Worth, H., Reid, A., Ackroyd, J. & Tamirata-Bowden, E. (2001). *Silence and secrecy: Refugee experiences of HIV in New Zealand*. Auckland: Institute for Research on Gender, University of Auckland.