Positive prevention: contemporary issues facing HIV positive people negotiating sex in the UK.

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ABSTRACT (173)

Over 40,000 people are now living with diagnosed HIV in the UK. The term ‘positive prevention’ has been coined to describe HIV prevention that focuses on people living with an HIV diagnosis. There is uncertainty, however, about how people with HIV manage risk and how their ability to prevent the transmission of HIV is specifically linked to mental health and social circumstances. We analysed 44 individual and 3 group interviews with the people most affected by HIV in the UK: black African heterosexual men and women and gay men (mostly white). We found that participants had similar as well as contextually different needs when it came to negotiating safe sex, assimilating prevention knowledge and establishing positive mental health. The themes that emerged included taking ‘additional responsibility’ for partners, negotiating with partners who are willing to have unprotected (anal or vaginal) sex, links with mental health, constructing the moral ‘other’ and power differences. We conclude with a discussion of the priorities for positive prevention for men and women living with diagnosed HIV in the UK.

INTRODUCTION

More than 40,000 people are now living with diagnosed HIV in the UK, the majority of whom are gay men (mostly white) and black African heterosexual men and women. (TheUKCollaborativeGroupforHIVandSTISurveillance, 2005). Helping people with HIV to improve their health, maintain their emotional wellbeing, and avoid passing the infection to others have emerged as major priorities for public health. This approach has been coined 'positive prevention', i.e. primary and secondary prevention which targets people who are living with diagnosed HIV (InternationalHIV/AIDSAlliance, 2003). As the number of people living with diagnosed HIV in the UK has risen substantially over the last five years, positive prevention has gained increasing importance.

Current approaches to preventing HIV transmission recognise that people make varying choices about the risks they are willing to take and that risk may be minimised yet not eliminated entirely (Bartos, McLeod, & Nott, 1993). Complex and sometimes contested discourses about HIV prevention have emerged as a consequence. People are required to make sense of their personal experience, varying circumstances and the proliferation of prevention approaches. The scope of these diverse approaches to risk include 'serosorting' for partners of the same HIV status for unprotected (vaginal and anal) sex (Elford, Bolding, Sherr, & Hart, 2007), and "strategic positioning" (a practice reported by some gay men where the HIV positive partner is receptive in anal sex and the HIV negative partner is insertive) (Elford, 2006).

Qualitative research has revealed narrative complexity in the way people assimilate HIV prevention messages and negotiate sex (Power, 1998). One finding to emerge is that real life sexual risk-taking and risk-reduction strategies are not well described by rational health models (Martin, 2006; Rhodes & Cusick, 2002). Indeed, people who take a 'rational' approach to sexual risk reduction may well under-estimate the importance of subjective experience and so be caught unawares when 'irrational' feelings such as intimacy and trust influence risk (Slavin, Richters, & Kippax, 2004). The accumulation of HIV narrative research over the years shows that a nuanced understanding of meanings, emotions, sexual dynamics and circumstance is essential for understanding HIV risk and prevention (Bartos, McLeod, & Nott, 1993; Davis,

Hart, Bolding, Sherr, & Elford, 2006; Davis, Hart, Imrie, Davidson, Williams, & Stephenson, 2002; Martin, 2006; Ridge, 2004; Rosenthal, Gifford, & Moore, 1998).

To date most research around HIV prevention in the UK among people living with - and at risk of - HIV has considered gay men and black African heterosexual men and women separately. For example, a considerable body of research has examined the reasons underpinning practices of risky sex among gay men including ' AIDS fatigue' and ideas that infection is inevitable; the transgression of social rules including sexual safety; using sex to deal with difficult emotions; men making assumptions about the serostatus of other men rather than talking about it; and even the operation of a 'death wish' among gay men (Carballo-Dieguez, 2001; Crepaz, Hart, & Marks, 2004; Grov, 2004; Halkitis, Parsons, & Wilton, 2003; Martin, 2006; Rhodes & Cusick, 2002; Ridge, 2004) Furthermore, not all condomless sex presents a risk of HIV transmission. 'Sero-sorting' involves discussing your HIV status with potential partners and avoiding unprotected anal sex with those considered to have a different HIV status. While a potential strategy for reducing HIV risk, there are concerns. For example, among people with diagnosed HIV unprotected sex of this kind might result in 're-infection' with more virulent or more drug resistant strains of HIV as well as other sexually transmitted infections (Halkitis & Parsons, 2003).

More recently researchers have examined sexual risk among Black African heterosexual men and women in the UK, many of whom were exposed to, and acquired HIV in Africa (TheUKCollaborativeGroupforHIVandSTISurveillance, 2005). HIV prevention knowledge among Africans in the UK is still relatively poor, (Chinouya, Ssanyu-Sseruma, & Kwok, 2003), in marked contrast to parts of Africa, although even in Africa the knowledge base may be mixed with misinformation as well as elements of denial (Kalichman & Simbayi, 2003; Walker, Reid, & Cornell, 2004). Whether due to denial, insufficient knowledge or both, many African people in the UK mistakenly view themselves as being at low risk for HIV. Consequently, a diagnosis of HIV frequently comes as a shock, and is associated with isolation and depression (Anderson & Doyal, 2004; Burns & Fenton, 2006; Chinouya, Davidson, & Fenton, 2000; Flowers, Davis, Hart, Rosengarten, Frankis, & Imrie, 2006). Recent research among black African men and women in London suggests that levels of risky sex are higher with regular partners than with casual partners (Elford, Ibrahim,

Bukutu, & Anderson, 2006). And like gay men some HIV positive Africans in the UK seek out HIV positive sexual partners as a risk reduction strategy (Chinouya, Ssanyu-Sseruma, & Kwok, 2003; Elford, Anderson, Ibrahim, & Bukutu, 2006).

No study has specifically investigated the contemporary sexual risk and prevention challenges facing HIV positive people in the UK. In this paper, we used a modified grounded theory approach to investigate personal positive prevention approaches. We used the theme of 'life journey' in semi-structured in-depth interviews (and theme-clarifying focus groups) to identify the significant sexual issues identified and prioritised by people themselves, rather than identifying these in advance. The key issues discussed in this paper include coping with threats posed by compromised mental health; protecting partners from HIV; and the challenges that negotiating sex poses to maintaining safe sex. The discussion investigates the broad perspectives and experiences of HIV positive people, highlighting how differing social circumstances and contexts are important for positive prevention.

METHODS

In this article, we draw on data from audio and video recorded interviews that provided the foundation for the development of a Web site covering experiences of living with HIV (www.dipex.org/hiv), which was launched in November 2006. During 2005, the first author conducted 44 individual and 3 group interviews largely with gay men and black African heterosexual men and women who were living with diagnosed HIV. People were encouraged to tell their stories in their own words about their experiences of living with HIV. To be eligible for the study, participants had to be over the age of 18 and have a diagnosis of HIV. The study was approved by the Multi Centre Research Ethics Committee in the United Kingdom

Sample selection and recruitment

We used principles of maximum variation sampling to recruit a diverse group of gay men and black African heterosexual men and women (Coyne, 1997). In the first phase of recruitment, 19 black African individuals (9 heterosexual men and 10 heterosexual women), and 25 gay men (20 white, 5 ethnic minority including 'white other') were interviewed, as well as one heterosexual male of east European origin. Because the approach to interviewing was slightly different for black Africans (see below), it was

decided to conduct a further 3 focus groups with black African individuals (2 groups each of 4 women, and 1 group of 4 men; these groups resembled participants interviewed individually) to clarify the analysis. This maximum variation sample was obtained through a variety of carefully selected avenues including specialist NHS HIV clinics, peer support groups, community organisations, Internet sites and newsletters. The diversity of the sample is discussed in the Methods section.

The interviews

Open-ended, in-depth interviews gave respondents as much time as required to talk about their experiences in their own words and to focus on issues about HIV, contemporary life and coping that were important to them. The concept of 'life journey,' with a special focus on HIV, was used to frame the interviews**.** With gay men, the researcher asked participants to begin talking from their early life experiences through to the present day. However, the experience of the clinicians in the research team was that many black African migrants to the UK would have highly traumatic past life histories. It was decided to (generally) begin interviews with black Africans from around the time of diagnosis with HIV so people could avoid discussing earlier traumatic events if they so desired. The interviewer adopted an approach that allowed all participants to define the boundaries of the information they volunteered, and some Africans did volunteer earlier life stories and traumas. A referral sheet with telephone and one-to-one counselling was provided to participants.

A topic list was used in the final part of the interview to ensure that broad topics of relevance to the study had been considered for discussion. These included getting tested and being diagnosed with HIV, experiences of health care, treatment issues, negotiating sex and relationships, disclosure to sexual and other partners, mental and physical health concerns, challenges to coping, social supports, personal coping strategies, feelings about the future, ageing and dying. Because of several high profile criminal prosecutions of people for reckless transmission of HIV in the UK at the time of the study, we agreed to focus data collection on unprotected anal and vaginal intercourse before people were diagnosed, the episode where people assume they were infected, and current challenges to practices of safe sex. Interviews ranged from 60 to 180 minutes and were audio – or video – recorded with the informed consent of

each participant. We use the term “unprotected sex” to describe unprotected anal and vaginal intercourse.

Analysis

The audio recordings from the interviews were professionally transcribed, corrected by the first author, and returned to each participant for review. The software MAXqda version 2 was used to aid the coding, organization, and searching of narrative sections from each interview. MAXqda enabled sections about themes across a range of interviews to be compared and linked for a systematic analysis. The first author identified emerging themes using a modified grounded theory approach and multiple levels of analysis as described elsewhere in the literature (Glaser & Strauss, 1967; Ridge, Minichiello, & Plummer, 1997). The analysis was a cyclical process: continually moving between reviewing the literature, data collection and coding, linking codes, and revising and reshaping the analysis. The analysis was scrutinized by other authors through regular meetings and electronic exchanges. All authors were involved in refining the final analysis and commenting on drafts of the paper.

Issues of complexity

It is tempting to make a straightforward comparison of the two main groups we spoke to: predominantly white gay men and black African heterosexual men and women. However, one of the aims of the study was to explore a broad range of perspectives and experiences, and a simple comparative approach risks prioritising sexuality and Black African ethnicity and so over-simplifying the issues raised in this paper. In particular, because we adopted a ‘maximum variation’ sampling strategy, there is much heterogeneity within the sample. As can be seen in Table 1 (which shows the characteristics of the 44 individual participants but not of the focus group participants), there was heterogeneity along a variety of dimensions including residence, biological sex, ethnicity, age, levels of HIV in the blood (viral load), reported health issues, treatments and years since diagnosis. All 9 women we interviewed were black African; most people with immigration problems were also black African. All diagnoses before 1990 were among gay men while black Africans tended to be diagnosed more recently. Only gay men reported using recreational drugs. In terms of commonalities, most participants were relatively healthy (very

few had a high viral load or low CD4 count), although there was a relatively high level of depression and suicidal thinking reported. Most of the people who described themselves as Christian were black African while gay men tended to describe themselves as "spiritual".

[insert Table 1 about here]

Both the success and limitations of the maximum variation strategy are evident in the way that hard to reach participants were included. For instance, we held individual interviews with 9 black African men and conducted one focus group discussion with African men: men who are often considered isolated and less willing to speak about their experiences of HIV than African women (Doyal, Anderson, & Apenteng, 2005). We were also able to locate 5 black, minority ethnic or non-British gay men for interview, including one black Caribbean man (but no black African men), two men from South America, one man from South-East Asia and one 'white other' man from France. There was in addition one gay man originally from Wales, one from Northern Ireland, and other men with Irish heritage. A white heterosexual male immigrant from Eastern Europe was also interviewed.

Some social dimensions are not so clearly evident in the table. For instance, as well factors associated with biological sex, there are also socially constructed gender issues. For instance, women with HIV risk being labelled by their communities as 'bad women', promiscuous or prostitutes (Doyal & Anderson, 2005). Throughout the text (below) we have tried to highlight some of the complexity introduced by biological as well as socially constructed differences and categories.

RESULTS

Negotiating sex

For all participants, the negotiation of safe sex required a specialised body of skills and knowledge. This is because the negotiation of sex is essentially a complex social interaction where individual as well as partner dynamics need to be taken into account, along with the specifics of circumstance (Ridge, 2004). Of particular concern in accounts that cut across the interviews were sexual partners who appeared willing to engage in unprotected anal or vaginal sex. However, the reasons for this

willingness varied somewhat between the gay men and the African women. Gay men talked about encountering sexual partners (casual and regular) who apparently did not have a HIV diagnosis, yet appeared to them careless or even willing to have unprotected sex. This could be the case even when the partner was aware of the positive HIV status of the participant. Such situations could be difficult for men to cope with emotionally, and required a good deal of resolve and skill to address. Here, men found they could be positioned uncomfortably as the sentinal for safe sex and the 'condom police.'

> I'd already told him [a casual partner] that I was HIV positive and he shrugged his shoulders. [Sniffs] And [um] you know, the proceedings start and he said, 'Let's not worry about the protection.' And I said, 'Well, you know, you're putting yourself at risk.' ….. I got angry [um] because I thought well I've done my best to sort of, to sort of protect you, and it's almost like you're throwing it back in my face. - WHITE GAY MALE, EARLY 50S

If the desire on the part of a HIV negative partner to have unprotected sex occurred in a steady gay relationship, it could put considerable pressure on the partnership. While there was acknowledgement that not using condoms could be about expressing an emotional closeness on the part of their partners, participants also suspected that there could be elements of self-destructiveness.

> My [regular] partner was a recovering alcoholic and both he and I felt there was an element of self-destructiveness within his willingness to take risks. I do think that some of the behaviour was due to the desire to be closer, since more often than not it was a case of passions rising and his delaying putting on a condom for as long as possible…. it was never an issue with me putting on a condom…. On the couple of occasions when I did not act as 'condom police' and let it happen, it resulted in full penetration. - WHITE GAY MALE, LATE 30S

> [My regular partner] was a bug chaser. And the more I tried to protect him… Because I didn't want it on my conscience. The more I tried to protect him, the more fights we used to have about it. And in the end I had to totally turn it round and be totally selfish and say, 'Well, if you get sick, who's going to look

> after me?' You know. And that sort of woke him up a little bit to that, you know…. He had a terrible upbringing… And I think he was in total self-destruct……. – WHITE GAY MALE, MID 30S

The narratives of the women focused mainly on black African male partners whom they considered ignorant – and in denial – about HIV. In the context of all the women's interviews, gender relations and the negotiation of power appeared to be important. Women described various methods used by men to try to overcome their resistance to having unprotected sex. Some women believed that men in particular are in denial about their risk of getting HIV, and as such can be somewhat determined in their attempts to overcome opposition to condomless sex.

> I don't want to take chances, we've been lucky. We've been lucky. We've been very, very lucky and like what the doctor told him [her partner] on Thursday at [name of HIV clinic removed] is that he's an adult, it's his choice, but for the sake that we are planning to have a child, if for anything I became ill in the future somebody has to be there for the child. So I beg that we please use condoms. - BLACK AFRICAN FEMALE, MID 30S

> A few African women I know… they've told men when they've met them you know… I'm positive, and they say 'No, no you're lying because you don't want me… that's why you're saying that.' - BLACK AFRICAN FEMALE, EARLY 30S

Women also reported men using more indirect means to avoid condom use, as well as men directly trying to talk them out of using condoms. Some pointed to the way men can capitalise on female desire: '…because when you are a woman you want it, you reach that stage…[they] throw the condom away. You can't throw him away.'

> But then again it was difficult because back there, and even here with black men I would say, when… They're not very keen on condoms at all, and it's very difficult. They sort of talk you out of it, they're not like… they don't really, it's not like they force you to do it, but they sometimes talk you out of it. And you then feel… as a woman, it's very easy to start feeling that… cos you're with a

> man, you want to please him or satisfy him, so you just want to do what he really wants you know. So yeah, that I found difficult … If I'm saying I want to use condoms…. Their mood could change… And then maybe they'll start complaining that you know, 'I'm OK, I'm fine, so why are you using condoms…?' - BLACK AFRICAN FEMALE, EARLY 30S

Gender relations were clearly important. Not having the power (i.e. the confidence, knowledge, skills and the right social circumstances) to negotiate safe sex was a problem noted by women in particular. In one dramatic account a women believed she became infected with HIV when she was raped by soldiers back in Africa. Many women suspected being infected by partners in Africa whom they subsequently discovered were secretly having unprotected sex outside their (hitherto assumed to be monogamous) relationship. There was also an anxiety among some woman that female assertiveness could end in conflict and violence.

> There's a man where we put a condom on, but in the middle of it, he removed it, and threw it away. I didn't know it, I didn't know it. But I did not dare say the condom was out. He said he doesn't like it with condoms. Now I don't know should… can I tell this man or should I keep quiet? I decided no, I leave it, because it will turn into something else. I tried. I did try. It was his choice. And I brought the condom. I gave it to him, I put it on myself, but in the middle he decided to remove it, so I can't do anything else… The problem is we women in this system, you don't want to add more violence on what you have. You might bring a different one, a stronger one, who will destroy you more, you see? - BLACK AFRICAN FEMALE, LATE 30S

However, the power of men conferred by gender relations was relative and not absolute. It was not always women who felt they lacked power; men also felt they lacked power at times. One man described becoming HIV infected following a sexual assault by another man. Some heterosexual men said they did not always feel they could assert safe sex with women (first quote below). In the second quote below, one younger gay man argued that young people – male and female - have fewer resources to negotiate safe sex successfully.

> I was going out with a girl whom I didn't trust... I felt like it was necessary for both of us, not only me, to go for a test… that should have preceded our relationship. But what happened was that I just allowed that [unprotected sex] to happen, and then we went for the test after. - BLACK AFRICAN MALE, EARLY 40S

> Because they (young people) don't know how to negotiate. Or you're still figuring out your boundaries and you know, what you want in life. And attraction to someone can be an extremely powerful force and being able to say no, or this is what I'm comfortable with or, you know asking the right questions about when they've been tested, not everybody's able to do that. - WHITE GAY MALE, MID 20S

Additionally, women's relative lack of power in sex is being challenged, especially as women gain social and economic power relative to black African men in the UK as well as in Africa (Doyal, Anderson, & Apenteng, 2005; Spronk, 2005). While it was clear that many women struggle to assert their needs with male partners, some women were able to insist on condoms with their men. This situation is neatly summed up by one woman:

> But from my friends that are going with black men, it's an issue, it's a big problem for them. There's a few of them that will insist [on condoms], and then you get the ones that it's difficult for them. - BLACK AFRICAN FEMALE, EARLY 30S

Mental health

A rewarding sex life and good mental health are considered key aims of positive prevention (InternationalHIV/AIDSAlliance, 2003). It was common for participants in general to go off sex in the short-term after the emotional upset of an HIV diagnosis, or during a period of illness (as one man said, 'being sick is not sexy'). But participants also talked about long term problems in having a fulfilling sex life, such as a lack of interest sex in relationships that was (at least partly) due to HIV: 'I don't have any doubt that one of the reasons the relationship wasn't sustained sexually was because of HIV,' said one gay man. People attributed problems in their sex lives to

the biological effects of the virus, medication side-effects, getting older and HIV-related psychological issues in partnerships. In terms of the latter, the narratives revealed ongoing problems associated with sex including anxieties about HIV transmission (first quote below), thinking excessively about HIV during sex, the emotional and social difficulties entailed in disclosing HIV status to new sexual partners (second quote) and sustaining intimate relationships (third quote).

> …sex is no longer enjoyable… because the person I am sleeping with, she always try to look whether the condom is, the condoms are OK… she cannot just tell you that she does not trust you, but you can see from the reaction… she is just fearing for her own safety. - BLACK AFRICAN MALE, MID 30S

> …before I would be the one that might go and approach somebody. But after the HIV, I was less confident because I thought I'm going to have to go through this stage of telling somebody.' - WHITE GAY MALE, LATE 40S

> Yeah I think it hurt me, the last relationship, when I split up with the negative guy. Although it was my decision it wasn't his you know…. So there's a bit of self-imposed isolation, there's also a bit of throwing myself into my work.' - WHITE GAY MALE LATE 40S

Women focused their discussions on avoiding sexual partners altogether, their difficulties in finding male partners who also had HIV (to avoid the possibility of passing HIV on), and avoiding problems associated with disclosing HIV status to male partners. In general, while some men talked about avoiding sexual intimacy especially in the aftermath of a diagnosis, they talked more about the way that having HIV could be a pre-occupation during sex, and so 'destroy the moment.' One of the key tasks identified in living well with HIV (a key aspect of positive prevention) was to avoid letting thoughts of HIV take over: 'I think it's because it just takes the fun out of sex if you start thinking about things. I don't let things take over.' As evident in the first quote below, thoughts of HIV were discussed as potentially compounding deeper (sometimes buried) feelings that gay sex was somehow 'bad' or 'shameful', and that unprotected anal sex was somehow taboo. The second quote reveals how

being less interested in sex because of HIV could be linked to feeling weak and so feeling less masculine for black African men (Doyal, Anderson, & Apenteng, 2005).

> I was raised an Irish Catholic... unfortunately the sexual side of things…. It is bad… The thought pattern you had… HIV just didn't go hand-in-hand with having good sex… I am thinking well I am going to do that, but HIV, HIV, HIV has sort of gone off in my head.' - WHITE GAY MALE, LATE 40S

> And in the African culture context, it's [not having sex] like denying… you are no longer a man. And it does impact very negative on them…. It is something you have to deal with mentally, it's nothing to do with HIV. - BLACK AFRICAN MALE, MID 40S

In contrast to the narratives of heterosexual individuals which linked their own risk taking to a lack of information, as well as denial, unprotected sex was frequently talked about by gay men (who were mostly well informed) as a realm of human experience that was 'accidental,' or where people were 'not thinking' or taken 'by surprise.' Below two gay men describe the circumstances in which they assume they were infected with HIV.

> I think we wanted to use them [condoms] but then we'd start getting hot and heavy, and didn't stop to think and put them on, much to my regret. - CARIBBEAN GAY MALE, MID 30S

> It was an accident. And that's the only thing I can think of because I was doing my best to try to avoid such risky procedures. - WHITE GAY MALE, EARLY 50S

These men talked about understanding the significance of their practice of unprotected sex in retrospect, as they reflected on their experiences and tried to make sense of them. Additionally, incidents of unprotected sex were frequently explained in terms of past unresolved mental health problems. A number of people connected the time they became infected to a period when they were down, not thinking clearly or when they weren't really coping. In the quote below, a young gay male professional

connects a sexual encounter (where he assumes he was infected with HIV) to a former, less functional self where he had not adequately dealt with 'coming out' issues and his dysfunctional early family life.

> I mean when you think retrospectively, well I thought I was a balanced gay guy. But there I was being fucked without a condom in a sauna by somebody I'd just met. [um] And, well, it's hardly balanced… You know, it's hardly the sort of thing that I would… if you'd asked me, I would have, have… have said that I did. And yet there I was doing it. So there was something going wrong in life in general. [um] And that was to do with, I think all these sort of different things that I've been able to… sort out, to some extent. Or acknowledge, simply acknowledge… The mind boggles as to what was going through my mind… not looking after myself. Working too hard…. Having become a bit of an automaton. – WHITE GAY MALE, EARLY 30S

By definition depression (which is commonly reported by people with HIV (Flowers, Davis, Hart et al., 2006)) means that your apparatus for thinking – the mind – has broken down to some degree (Ridge & Ziebland, 2006). The gay man quoted below described his experience of depression succinctly as 'a void of thinking':

> And that was a real thing of just not actually…. it was actually not, it wasn't this … it wasn't the pleasure kind of thing or the excitement or the connection on some level. It was just there was nothing there, the equipment wasn't there… the… it just, and all I could do was really shrug my shoulders, it was a void of thinking about it. And again, that's … because it feeds into sort of you know, issues of depression at that time as well. – WHITE GAY MALE, LATE 30S

The linking of alcohol or substance use to sexual risk was also discussed by gay men, although this was not a common link made by the heterosexual people we talked to. A number of gay men linked substance use to the time they became infected, suggesting that substances had played some role in their capacity to think about – and use – condoms during sex: '[drugs] make you less careful… you take risks.' But clearly, while men connect forgetting and lack of awareness with substance use, the narratives also suggest that men can still make choices at some level. Years later, while listening

to the radio about a HIV conference, one man (quoted below) recalled a forgotten drunken night when he believes he was infected with HIV where not using condoms 'seemed like a good idea.' As evident in the two quotes below, some participants more clearly acknowledged that they were able to make choices about condom use even when using substances, particularly if they were motivated to use condoms before using substances.

> And I suddenly had this awful remembrance of a very drunken night… And thinking 'bastard.' And then I remembered that neither of us had a rubber. You know, it seemed like a good idea. I don't do sex drunk. Normally. – WHITE GAY MALE, EARLY 40S

> I can't take clothes off…. I was really shy. I don't know what to do… And that's the very first time we had sex. But I don't feel shy. You know… because I am on drugs… Ecstacy was working for me. And that's… that's the very first time I have sex… But even then I'm very sure… you know, [we] used condoms and everything. - ASIAN GAY MALE, MID 30S

Meanings, responsibility and distancing from the moral 'other'

Participants in general were very concerned about the potential to transmit a virus that could seriously harm their sexual partners. Not surprisingly then, the meanings of risky sex were very much bound up in discourses about responsibility and morality. Given the methods used, we would not expect people to discuss morally suspect behaviour. Indeed, far from describing carelessness or malevolence toward their sexual partners, participants expressed considerable aversion to the thought of passing HIV onto anyone else: 'I'd be horrified at the idea of passing HIV onto anybody,' 'I would not want to pass this on to anybody… My conscience wouldn't allow me.' While there was recognition that sexual partners should take responsibility for themselves, in practice, people frequently described how they took *additional* responsibility for their partners. For instance, some people decided only to meet other HIV positive partners and one male used three condoms at once (even though this is not recommended) in an attempt to increase safety for his partner. In the quote below, a woman outlines her deep sense of responsibility to disclose in relationships regardless of the consequences.

> And a lot of my friends tell me… you kept this man alive, now he took another woman and left you. If you had kept quiet to yourself (about HIV) you would be together. I say that is not my life. That is not my life. My friends blame me, if you had not told this man, if you had just carried on. You lived together, he would also be positive like you, you would be together. Now he is with another woman. Why? You are suffering now. But I said 'It doesn't matter. I saved somebody's life, I have saved many.' – BLACK AFRICAN FEMALE, LATE 30S

Some people admitted to fantasies about having unprotected anal or vaginal sex with someone of unknown HIV status. This could be a way of coping with thoughts about becoming infected with HIV, anger at being infected with HIV and blaming someone else for an infection. A number of people admitted previously having fantasies of intentionally having unprotected sex or even going out to infect others with HIV. Strong currents of anger and hurt were clearly evident in the narratives associated with blaming someone else, and many talked about impulses that arose to act out their fantasies. Yet all such fantasies of not using condoms (first quote below) and intentionality (second quote) were couched in discourses about how HIV positive people managed to find ways to cope with their difficult feelings, rather than act them out.

> For a while in your mind you kind of flirt with the idea of saying, 'Well, I got positive anyway, while having safe [sex]. What's the point in have protected sex? You know, your mind's worrying away…. Particularly as you're sat there having these… you know, having started the drug regime. And going hmmm…. And then you think well no, if I go on that…. What kind of road is that going to take me on? It's not really something I want to go down. - WHITE GAY MALE, LATE 30S

> The first time you find out you are HIV, the first reaction … Since you don't know who give it to you, you want to spread it. It took a lot of self courage and discipline… I said to myself it's… It was my carelessness. So why should I

> want to put somebody else through what I'm going through? - BLACK AFRICAN FEMALE, MID 30S

Nevertheless, participants talked about other people with HIV they knew of – or had heard of – who were engaging in unprotected sex, or even intentionally spreading HIV, in what appeared to be exercises in 'moral distancing' (Ziebland, Wyke, Seaman, Fairhurst, Walker, & Glasier, 2005),

> And that is the attitude the African man goes about it. They want to spread it, they want to give it to as much people as they can…. Because they don't know who they got it from, it's a kind of pay back thing… Women do it, women do it too. - BLACK AFRICAN FEMALE, MID 30S

The wide currency of stories about the dangerous 'other' served as a contrast to the narratives of responsibility that participants attributed to themselves. We would also expect that the criminal prosecution of people for transmitting HIV in the UK could also feed into polarised discourses of the responsible 'us' vs. wanton others. One man said of criminal prosecutions: 'It really feeds into the good gay/bad gay thing… I have to make a special effort to be a good gay.' For black African participants who felt particularly vulnerable to negative media portrayals (Flowers, Davis, Hart et al., 2006), the threat of prosecution seemed a very present danger: '… it's a problem to go out with somebody who is not HIV positive. You might end up in jail.'

Consistent with the qualitative HIV literature, people attributed a wide variety of meanings to unprotected penetrative sex. For instance, heterosexual men talked about condomless sex as 'natural,' real sex, while gay men talked about condomless sex more in terms of transgressiveness. There was divergence in the narratives when it came to discussions about the meaning of condoms. In one corner, men and women were perplexed about why others could find condoms so difficult:

> Using that condom, I am just feeling like I am not using a condom. It's just the same to me.' - BLACK AFRICAN FEMALE, EARLY 40S

> If you automatically assume you are going to have safe sex, then you just do. - WHITE GAY MALE, EARLY 40S

> I don't believe it is difficult to practice safe sex. - WHITE GAY MALE, MID 30S

> From the very beginning she [my wife] decided straight away to stay with me…. And, we just use condoms like that. It's no problems at all. - WHITE HETEROSEXUAL MALE, late 40s.

At the other end of the spectrum were others, mainly men, who really struggled with the physical and emotional losses involved in using condoms. Here, condoms were considered awkward to use, diminished pleasure and interrupted intimacy and other valued meanings during sex. In the first quote below, a gay male declared he really 'hated' condoms, while many black African men used metaphors of taste to describe how condoms detracted from pleasure (second quote).

> To be very honest, I don't like using condoms it's awful… it's painful you know to be very honest. I don't like it. - LATINO GAY MALE, MID 30S

> There's no man who would not like having sex without a condom because it's like eating, you know a sweet with a wrapper on, you know you won't get the taste of it. - BLACK AFRICAN MALE, EARLY 40S

Constructing HIV risk

Although white gay men were generally very knowledgeable about ways of preventing HIV transmission, this was less true on the margins of established gay culture. With a Catholic upbringing that said gay sex was wrong, one Asian man (who had only recently come to the UK) actively assimilated the safe sex advice other gay men were giving him to his Catholic belief system as: 'all gay sex was unsafe.' One young man who seroconverted at the age of 17 said that information about preventing HIV transmission in male-to-male sex was not available in his school. He partly attributed his seroconversion to lack of information, as well as a youthful lack of skill in negotiating sexual relationships.

> I think you… you know, at 17 I was very naïve, I was very young, very believing. And when I was lacking confidence it was because I just didn't have all the knowledge. I wasn't worldly enough, I was just you know kind of, newly arrived and wanted to experience life and learn as much as possible. But if you don't have all of the information and knowledge at school you know it boils down to luck. - WHITE GAY MALE, MID 20S

The availability of reliable information about HIV transmission was reported as being relatively poor in African communities in the UK, although this is not always the case in Africa itself, as discussed previously (Kalichman & Simbayi, 2003). While black African participants discussed denial operating among 'other' black Africans, they tended to link their own infection to a lack of information: These participants in the main believed that they themselves only became adequately informed about HIV prevention *after* their own diagnosis with HIV.

> We were not even using condoms back home, we were just using direct sex. And they were telling us to use some sort of medication so that your vagina will be dry… I found out about how HIV transmits when I was here, when I was diagnosed. Yes that's when I learnt that condoms are best. - BLACK AFRICAN FEMALE, EARLY 40S

African men and women in particular were very concerned about the lack of reliable prevention information in their communities, and the myths that surrounded HIV transmission (e.g. Aids being due to witchcraft, HIV being white man's propaganda and HIV being contracted through everyday social activities like sharing cups). It is clear that HIV information is not absorbed passively (Bartos, McLeod, & Nott, 1993). Instead, information is actively assimilated to belief systems that people already have, whether it be constructs of masculinity which contain stories of men as clever, invincible and transgressive (first quote below), or post-colonial anxieties about the role of Westerners in the African AIDS epidemic (first and second quote).

> But my partner who I have been with for 14 years now. OK? I had suspected that his late, ex-wife had actually passed away with it…. I always said to him

> like ‘Go get tested.’…. He will not accept it [HIV] exists. He believes that it’s just propaganda. It doesn’t exist. And even if it does, it wouldn’t touch him. Because he is smart. I know it doesn’t make sense but… That’s the way he makes sense of it. It just would never come knocking on his door. - BLACK AFRICAN FEMALE, EARLY 40S

> A lot of [young Africans in the UK] are anti-condom….. they think they [condoms] are infected… They’re poisoned… They think that it’s… and I have to use these words, ‘a white man’s way of poisoning them’…. They think the poison… makes you impotent and never have kids, they actually believe… rumours slashed around a long time ago in Africa…. But I am surprised they’re still slashing around now…. Yeah a white man’s conspiracy. Aids is still seen as a white man’s conspiracy and it’s [condoms] something that they wouldn’t want to use. - BLACK AFRICAN MALE, EARLY 40s

While public health advice to use condoms for anal and vaginal penetration was widely embraced by participants, there were also parallel and conflicting discourses about HIV prevention. People were aware (sometimes from painful experience) that some people are infected the first time they have unprotected penetrative sex: ‘It was sort of like Michelle Fowler on Eastenders. The one time she had a shag, she got pregnant,’ said one gay man (Note: EastEnders is a long running BBC television soap opera about working-class people in London’s East End where the Michelle Fowler character had a teenage pregnancy). On the other hand, there were also firsthand experiences of (and popular stories about) HIV positive people having considerable unprotected sex, even with HIV negative partners over a period of years, without transmission occurring.

> ‘We’ve had unprotected sex for about 30 times, and he is still not positive. Is it the medication or…? And the doctor told me that you could be positive from sleeping with somebody just once, and you don’t know when it is. That is the risk. - BLACK AFRICAN FEMALE, MID 30S

A few gay men in particular had assumed they were HIV positive because they had frequent unprotected sex with a regular partner who had HIV, and yet they

subsequently found through testing that they had not at that stage contracted HIV. People attributed differences in HIV transmissibility in risky sex to luck, differences in immunity and differences in infectivity due to treatment induced viral load reductions in the body.

For some gay men despite a high level of uptake of public health discourses that HIV can be avoided, there was a sense that their infection was inevitable. One male health professional wrestled simultaneously with conflicting discourses: that condoms were essential to prevent HIV transmission; that HIV was inevitable for those in risk categories; and that some people are immune from HIV: 'Some people aren't going to get it, they've been quite lucky even though they've been unprotected… it doesn't matter how unsafe they are, they're not going to get it anyway…. You have that suspectibility to it, or you're not.' The fact that this man was a long-term survivor (10 years) without requiring medication also seemed to fit with his theory of differences in personal susceptibility to HIV.

DISCUSSION

This qualitative study is one of the first to thematically investigate 'positive prevention' among people living with HIV in the UK. While there has been an historic reluctance to design specific HIV prevention interventions for people living with HIV (van Kesteren, Hospers, Kok, & van Empelen, 2005), the current study shows that HIV positive people living in the UK do indeed have very specific prevention requirements because they are HIV positive. Additionally, HIV positive individuals describe certain common – as well as varying – needs when it comes to preventing the onward transmission of HIV.

Our research revealed some concerns involved in negotiating sex. Even though many said sexual partners should take on greater responsibility, participants in general described taking on *additional* responsibilities for the protection of their sexual partners. Coupled with notions of high personal responsibility, the narratives also suggested that a high level of negotiation skill was required to avoid passing HIV on e.g. with partners willing to have unsafe sex. Research in the Netherlands has also found that many HIV positive gay men take on additional responsibilities to prevent HIV transmission to their partners (van Kesteren, Hospers, Kok et al., 2005). The

current research extends a similar construction of ‘responsibility’ beyond gay men to also include black African individuals while identifying the concept of over-responsibility.

Additionally, this study revealed some distinct differences in the sexual negotiation issues participants were facing. In terms of gender for instance, women focused their discussion more on men who seemed to be ignorant and in denial about the risks of HIV, and so tried to overcome women’s resistance to having sex without condoms. However, for gay men, the focus was less on the denial side of HIV risk and more about partners who appeared willing to have unprotected sex despite a degree of awareness of the risks. Many participants described how they could be positioned in negotiations as the sentinels of safe sex, and yet the skill-set required by HIV positive people to undertake this role in sexual relations is as yet little recognised in the literature (InternationalHIV/AIDSAlliance, 2003). There is much literature on the relative lack of power women have to negotiate safe sex (Amaro, 1995; Nyanzi, Nyanzi, Kalina, & Pool, 2004; Pulerwitz, Amaro, Jong, Gortmaker, & Rudd, 2002; Wingood & DiClemente, 2000), and our findings fit well with this literature. However, our research suggests that men can also feel relatively powerless under certain circumstances. There is evidence that African women can have more power than their male partners in the UK (Doyal, Anderson, & Apenteng, 2005). These results remind us that power can be in flux according to a range of individual characteristics and social circumstances (Ridge, 2004).

One of the most striking inequalities between white gay male participants and non-white participants in the current study was in access to consistently reliable HIV information and resources. Black Africans in particular were coming to terms with high levels of denial, fear and stigma, lower levels of initial HIV prevention information and fears of deportation and exclusion from effective treatments. White gay men reported, in comparison, a climate of relatively low HIV stigma, high levels of HIV prevention information and measured confidence in accessing effective treatments. For immigrants to the UK, most of whom had come from Africa in recent years, past practices of unprotected sex were related to a lack of information about HIV. The assimilation of effective HIV prevention knowledge was also reported as an issue for gay men on the margins of established white gay culture (e.g. those recently

out of school, migrants from South America or South-east Asia). All these individuals became educated about HIV prevention only after diagnosis. Clearly, HIV education efforts in the UK and elsewhere could be better targeted towards these individuals before they become HIV positive.

Interestingly, counter-discourses about HIV prevention which challenged official health promotion discourses did resonate with a number of participants. These counter-discourses (e.g. HIV as a white man's conspiracy, certain people being immune to HIV, HIV being inevitable for some people) are similar to the 'folk discourses' about HIV which are well documented in countries like South Africa, Botswana and Tanzania. Here, local discourses (e.g. about witchcraft causing at least some cases of AIDS, as AIDS being due to disrespect for traditional ways) are thought to be developed and transmitted orally (Heald, 2002; Mshana, Plummer, Wamoyi, Shigongo, Ross, & Wight, 2006; Stadler, 2003). We found that 'folk' or 'counter' discourses were not confined to black African participants in the UK, emerging through a rich mix of personal experience and the telling of stories. However, it is not yet clear how these counter-discourses are impacting on behaviour in the UK.

There is a growing literature on the mental health of HIV positive people, and the implications for sexual risk (O'Leary, Purcell, Remien, & Gomez, 2003; Parsons, Halkitis, Wolitski, & Gómez, 2003; Schiltz & Sandfort, 2000). The current study contributes to this literature by revealing some narrative evidence about the ways in which mental well-being is linked to sexual wellbeing and risk among HIV positive people. There were similarities and differences between the narratives. In terms of similarities, there was discussion about the problems of establishing fulfilling sex lives among all participants. Various psychological reasons were provided, including obsessive thinking about HIV, anxiety and fears of rejection. In terms of variations, women talked about a shortage of HIV positive partners and at times their avoidance of getting into emotional relationships, Men on the other hand had to deal with potential threats to their masculinity posed by having HIV. For instance, black African men talked about initially feeling weak and so less masculine.

Related to feelings of anger and blame, the current study found that some participants had to manage fantasies of having unprotected sex (sometimes even including fantasies about intentionally infecting others). The participants in the study were evidently managing their difficult feelings surrounding their diagnosis well. But the findings hint at the mental health needs of people with HIV who may be managing these impulses less well. The narratives suggest that issues of unprotected sex and intentionality could be more usefully understood as unmet mental health needs, rather than an issue that could be effectively pursued through legal avenues. The results also show that there is an important split among HIV positive participants in terms of the acceptability of condoms. For some, usually women (but also some men), the thought of using condoms is not difficult. For others, mostly men, the notion of using condoms represents a substantial loss in physical pleasure and symbolic meaning in their sex lives. This finding suggests that embodied maleness and socially constructed masculinity are important considerations in sexual risk. We need to take more seriously the way men experience themselves in their bodies as well as in terms of social representation (Robertson, 2006), starting with the grief men experience over the multiple losses involved in using condoms.

Within the context of relatively high levels of information about HIV prevention, unprotected sex described by white gay men was frequently constructed as 'accidental' and as a kind of behaviour that could be better understood in hindsight. Some gay participants linked their mental health concerns and substance use to practices of unprotected sex. Gay men attributed (or perhaps at times justified) the resultant potential and actual risky sex as a kind of cognitive disconnect. While certainly evident in the data, there was a lot more going on here than just 'hot cognition' described by Gold whereby people dispense with condoms in the 'heat of the moment' of the sexual encounter (Gold, 2000). For instance, people also talked about how their thinking in general (including during sex) could be devoid of much thinking at all. Because depression involves ineffective and distorted thinking by definition (Segal, Williams, & Teasdale, 2002), it can reduce the capacity of people to think about using condoms, along with much else.

Given that understanding personal mental health problems is a project that happens over time (Ridge & Ziebland, 2006), it is perhaps not surprising that gay men

constructed their understanding of their risky sexual behaviour as emergent rather than instantaneously available. That is, unprotected sex is something that could be better understood in hindsight after the event. This result shows that not only do rational models of sexual behaviour fail to account for much unprotected sex, so too do narrative approaches that construct subjects as already knowing agents and narrators of their sexual lives. What the findings here point to is the way that the reasons for unprotected sex – and even the experience itself - can at times be outside the realm of conscious awareness: 'The mind is very capable of blotting out things it wants to forget,' as one man put it. This does not mean that men do not make choices and so are not responsible for their behaviour. On the contrary, somewhere along the line, choices are made, but not always in a way that clearly reveal or acknowledge agency. That reducing HIV risk may not be a priority in conscious awareness at the time of sex, or after sex, has received very little recognition from qualitative researchers in the literature to date. Further research in to the way that narrative accounts of sexual risk are gathered together over time would be a worthwhile endeavour.

Media stereotypes of dangerous gay and black African individuals intent on infecting other people were not supported by the data. However, it was interesting that there were many stories collected in the data about the moral 'other' who intentionally has unprotected sex or tries to infect others. The evidence that this group of HIV positive people is probably very small in the UK (Elford, Bolding, Davis, Sherr, & Hart, 2006), appears to contradict these narratives which have relatively wide currency among participants in this study. It is interesting then that the respondents themselves adopt and deploy discourses to distance themselves from bad gay men and African individuals. These stories appear to function as dualistic tales of morality, establishing the 'other' and articulating behaviour that is and is not acceptable for HIV positive individuals. These stories work to police the high expectations of responsibility of the HIV positive individual. They do not appear to reflect any accurate epidemiological picture.

There were some limitations to this study. We were able to interview only people who were willing to talk about their HIV, so we are unlikely to have identified some of the most isolated and ill. Our participants mainly regarded themselves as being in good

health (but not always), and were willing to help others by having their story on a Web site (www.dipex.org/HIV). They were likely to be "role models" for coping with HIV. Additionally, when conducting interviews in a country where people are currently being prosecuted for transmitting HIV, there is an understandable hesitancy on both the part of the researcher and the participant to discuss an activity that is potentially illegal. So it was not possible to know in the current study the extent to which people's stories of current day success in maintaining safe sex matched their lived experience, nor the extent to which participants interviewed represented those living with HIV in the UK. For instance, we have already outlined earlier the success and limitations of recruiting a culturally diverse group of participants. In addition, narrative research in the Netherlands suggests that it is possible to locate HIV positive individuals who are willing to talk about their current practice of risky sex, a minority of whom claim to feel little responsibility for ensuring safer sex (van Kesteren, Hospers, Kok et al., 2005). Finally, the issue of disclosure of HIV status to sexual partners requires special attention and is covered in more detail on the website www.dipex.org/hiv.

Despite the limitations of the study, there is good reason to have confidence in the value of the data for the purposes of exploring a wide range of meanings behind sexual risk. While we do not claim numerical representation (this is not the purpose of maximum variation sampling), we are confident that we have a sample that can reveal a broad range of experience and complexities with regard to HIV positive people negotiating sex in the United Kingdom. We made substantial efforts to include people who are most affected by HIV in the UK: gay men and black African heterosexual men and women. The analysis points to the critical importance of identifying the key narratives related to negotiating safer sex (primary prevention) and promoting mental health (secondary prevention) for people with HIV in the UK. This study contributes to the positive prevention literature by highlighting the priorities of participants and their current concerns. Additionally, it shows how the social circumstances of the people most affected by HIV in the UK shape their positive prevention needs.

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