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Uncertainty and 'technological horizon' in qualitative interviews about HIV treatment

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ABSTRACT Highly Active Anti-Retroviral Treatment (HAART) has reduced death and morbidity among people with HIV. However, HAART is not always effective, can produce serious side-effects and implies uncertainty for patients. To address HAART-related uncertainty, 20 qualitative interviews were conducted with gay men with HIV in Glasgow and London. The interviewees were purposively selected to reflect diversity in terms of year of diagnosis, experiences of illness and treatment-related side-effects. The interviews were analysed using the constant comparison method to derive themes. Among those using HAART, analysis identified themes of 'good health', 'illness' and 'loss of confidence'. Uncertainty was managed through a discourse of 'technological horizon' that combined the ongoing innovations of HAART and biographical time. These themes are discussed in terms of the implications for HIV care. In particular, technological horizon provides a basis for the management of uncertainty in the prescribing relationship between patient and clinician.

KEYWORDS *gay men; HIV treatment; innovative health technologies; qualitative research; uncertainty*

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Introduction

This article employs qualitative methodology to address treatment-related uncertainties in the lived experience of gay men with HIV. Highly Active Anti-Retroviral Treatment (HAART) was introduced in the mid-1990s in the affluent West, leading to improved life expectations (Health Protection Agency, 2004). For people with HIV and their carers, effective HIV treatment has been linked with dramatic changes in lived experience and in clinical practice (Green and Smith, 2004; Rosengarten et al., 2004). Central to these adjustments are the uncertainties of the 'post-HAART' situation. Side-effects, the development of drug resistance and treatment intolerance can undermine the long-term effectiveness of HAART (NAM, 2003).

The 1996 Vancouver AIDS Conference is generally taken as the date when the epidemic began to change for the better (Holzemer, 1997). At this conference, evidence was provided that combinations of anti-HIV drugs effectively reduced viral activity, protecting or restoring the immune systems of people with HIV. Subsequently, the advent of HAART has come to be represented as a definite medical watershed in the history of the epidemic. Accordingly, the situation is variously constructed as post-HAART,¹ post-AIDS (Dowsett, 1998) or as 'living after crisis' (Rofes, 1998). HIV infection is now referred to as a chronic manageable infection (Siegel and Lekas, 2002), while public policy for prevention and treatment has become normalized (Rosenbrock et al., 2000). However, a review for the British HIV Association noted that psychological morbidity for people with HIV was associated with ongoing uncertainty about HAART (Green and Smith, 2004). In addition, for people with HIV from Africa and living in the UK, uncertainties about using HAART were sometimes displaced by concerns over right of abode and access to treatment (Flowers et al., 2006). Uncertain citizenship and implied lack of access to HAART overshadowed the technical uncertainties of HAART.

Much research about the post-HAART situation has adopted a chronic illness model (Green and Smith, 2004). Such research has focused on the difficulties of the post-HAART situation and the support needs of people with HIV (Kalichman et al., 1998; Bogart et al., 2000). This research has elaborated on the general themes of hope and uncertainty, often with the aim of establishing frameworks for psychosocial support for the daily management of pill taking, side-effects and mental health. For example, researchers have explored the impact of HAART side-effects on people with HIV. In particular, lipodystrophy (changes in appearance related to loss of body fat) has been linked with difficulties in sexual practice, treatment adherence and well-being (Dukers et al., 2001; Duran et al., 2001; Oette et al., 2002; Power et al., 2003). Researchers have also used qualitative methodologies to explore the lived experience of the post-HAART situation. A central concept has been 'revival discourse' used by people with HIV to engage with expanding life options, coupled with uncertainty

about the long-term effects of treatment (Brashers et al., 1999; Trainor and Ezer, 2000). Developing this uncertainty thesis, research has mapped out the cognitive coping strategies of gay men with HIV infection and identified how they valued autonomy and control, both of which provided strategies for deconstructing life with HIV, preparing the self for uncertainty and reducing stigma (Siegel and Schrimshaw, 2000).

Researchers have also investigated the challenge of uncertainty for clinical practice. In general, the uncertainties of HAART are regarded as a problem for the development of evidence-based prescribing practice. For example, a systematic review attempted to deal with uncertainty and decisions about commencing HAART (Wood et al., 2005). UK best practice guidance also refers to the incompleteness of the evidence base for clinical practice (<http://www.bhiva.org/guidelines/2005/HIV/HIV05frameset.html>, 1 December 2005). Uncertainty arises because clinical trials demonstrate the efficacy of particular treatments, but they do not provide data for long-term, routine clinical practice, such as for patients who change their treatments because of side-effects and intolerance. Partly as a result, researchers have explored the dilemmas faced by HIV clinicians themselves (Gerbert et al., 2004; Rosengarten et al., 2004; Williams et al., 2004). Uncertainties in treatment outcomes can be reflected in self-reported stress and anxiety among clinicians (Williams et al., 2004). Gerbert et al. (2000) advocate for 'relationship-centred HIV clinical care' as a way of managing treatment uncertainty, both for the patient and the clinician.

However, much of the research conducted since the advent of effective treatment is not reflexive with its own assumptions about the post-HAART situation for people with HIV, although there are some notable exceptions from the cultural studies of medicine and the body using post-structural theory. Writing in the period before HAART and drawing on Foucault, Heaphy (1996) noted how HIV medical technologies created new options for people with HIV along with additional forms of self-surveillance. Working in the cultural studies of science and technology, others have developed this Foucauldian theme for the post-HAART situation. Race has explored the new forms of surveillance inspired by the capacities of HAART, identity and the new forms of social relations in clinical care (Race, 2001a, 2001b). Persson (2004, 2005) has addressed how the side-effects of HAART are implicated in a reconfigured body with HIV and how gay men with HIV resist and rework the meanings of changed body appearance. Rosengarten (2004) has explored the consumer politics in the social marketing of HIV treatment. Stephenson (2003) argues that the reflexive practices associated with HIV treatment are also forms of self-subjection. Such self-subjection is revealed in psycho-medical discourse about the individual and their well-being (Holt and Stephenson, 2006). Perspectives such as these imply that the chronic disease/uncertainty research of the post-HAART situation relies on a deficit model where people with HIV are seen to lack the skills needed to cope with their life

with treatment (Adam et al., 2003). This deficit approach also reinforces a system that divides the knowledge and labour of caring so that professionals are seen to apply expertise to patients in need. This kind of arrangement sits at odds with current moves in HIV clinical practice in particular and the 'expert patient model' approach for chronic illness in general (DOH, 2001). A related problem of the deficit model is that it focuses on the training and development needs of clinicians, overlooking and devaluing the contribution of patients to making HAART work (Persson, 2004; Rosengarten, 2004). Such research also fails to engage with contribution of the treatment advocacy movement to patient–doctor relations and the practice of HIV treatment (Epstein, 1996; Race, 2001b).

Critical perspectives about the post-HAART situation also lead into questions about the view that uncertainty is always negative. In much of the research and intervention that supports care for people with HIV, uncertainty is seen as something that threatens people and that has to be minimized or compensated through emotional support. In this view, uncertainty is also seen as the opposite of the hope that is embedded in the promise of biomedicine. However, uncertainty may not be singular and disabling for the individual. Moreover, it may not be the antonym of hope. Working in the area of political theory, O'Malley (2000) has identified the positive value of uncertainty for individuals. In this view, uncertainty is a more neutral resource for active social agents. Lupton (1999) has discussed how 'edgework' in the face of danger is used to find a way of proving oneself, securing social status, achieving maturational milestones and presenting identity. Given that uncertainty is not always singular and detracting, we are left with a question about why research about the lived experience of the post-HAART situation constructs uncertainty as negative and against hope. One possible reason is that treatment uncertainty threatens not only the individual but also the capacities of biomedicine. The chronic illness research often makes the point that uncertainty may jeopardize the willingness of individual patients to continue to take HAART properly, therefore leading to the risk of poor treatment and the development of drug-resistant forms of HIV (see Lee et al., 2002). A related fear may be that patients may question clinical expertise when uncertainties become overwhelming. It appears therefore that the uncertainty thesis is not only relevant to the lived experience of individuals, but also to the governance and status of biomedicine in the area of HIV and beyond.

The sociology of expectations provides another way of developing research about HAART-related uncertainties. Outside the area of HIV, researchers have begun to map out the sociological aspects of expectations connected with technologies, including health technologies (Webster, 2002; Brown and Michael, 2003). This research foregrounds the social aspects of technological innovation, the related implications of uncertainty and the expectations of technology consumers. Prior to the advent of effective HIV treatment, Macintyre (1999) interviewed long-term survivors about their

experiences. One finding was that changes in the prognostic practices of HIV medicine linked to accumulating data and evolving knowledge about HIV sometimes undermined the hopeful expectations of people with HIV. Similar perspectives have emerged in research in the post-HAART situation, where limited clinical prognoses clash with both personal expectations and post-HAART discourse about the effectiveness of HIV treatment (Davis, 2005). In addition, research suggests that not all people with HIV deal with treatment-related uncertainties in the same manner, therefore questioning the totality and universality of treatment expectations (Davis et al., 2002). Exploring personal engagements with HAART and uncertainty, Ezzy (2000) identified several different narratives employed by people with HIV: 'linear restitutive'; 'linear chaotic'; and 'polyphonic'. Ezzy argued that linear restitutive and chaotic narratives were future oriented, entwined with the management of uncertainty and tied to the achievements of biomedicine in treating HIV infection, but respectively hopeful or pessimistic about the life course. Polyphonic narratives were present oriented, less embedded in a sense of linear, biographical time dependent on HIV treatment innovation and therefore less subject to uncertainty. Ezzy's work therefore points out the diversity among people with HIV in connection with HAART and uncertainty about the life course. There is a need to develop critical research about the interconnections between HIV treatment innovation, life expectations and uncertainty.

This article therefore makes several new connections in research about the post-HAART situation with reference to the reflexive treatment practices of people with HIV and the critical perspectives of theoretical research about HIV treatment and biomedical technologies in general. In particular, this article uses a qualitative interview methodology to question: the deficit model of the chronic disease approach to research and intervention in the post-HAART situation; a categorically negative view of treatment-related uncertainties; the ideological properties of the hope invested in treatment innovation; and the interplay of uncertainty, expectations and treatment innovation.

Methods

Background

This research is based on 20 qualitative interviews with gay men with HIV, conducted for the 'Transitions in HIV treatment' project, funded as part of the ESRC Innovative Health Technologies Programme (<http://www.york.ac.uk/res/iht/>). This project had several components, including: 68 interviews with people with HIV living in Glasgow and London (including gay men, injecting drug users and people from Africa residing in the UK); 16 interviews with carers and treatment advocates; a literature review of the way risk identity is operationalized in the medical science underpinning HIV treatment innovation; and a textual analysis of social marketing

of HIV treatment. One of the central aims of the project was to provide an account of the impact of effective HIV treatment on HIV positive people's experience of the disease, their changed understanding of their bodies in relation to HIV medical technologies and the assimilation of this knowledge into their identities. Another aim was to explore two different social and clinical settings (Glasgow and London), with a view to developing an account of transition that would be relevant beyond London, where most clinical research is done in the UK. Two areas of the analysis have been reported: the perspectives of people from Africa (Flowers et al., 2006) and HIV clinicians (Rosengarten et al., 2004). This article therefore addresses the lived experience of gay and bisexual men living in Glasgow and London. The qualitative interview research adopted an iterative, inductive methodology (Strauss and Corbin, 1998).

Sampling

Volunteers for the interviews were recruited from HIV outpatient clinics in London ($n = 10$) and in Glasgow recruited both through clinics and a local HIV charity ($n = 10$). The samples were broadly representative of the gay male clinic populations (see Table 1). The volunteers were aged between 28 and 55. The London sample reflected the ethnic diversity of that city. Two interviewees had an African background and one had an Asian background. Nine of the interviewees were diagnosed prior to, or during, the HAART watershed in 1996. Four participants had never taken HAART. Eleven interviewees were diagnosed with HIV infection after 1996.

The interviews

The interviews were conducted between July 2001 and June 2002. The same topic guide was used in Glasgow and London. The interviewees were asked to talk about their experiences of using HAART, with a focus on lived experience before and after the introduction of HAART in 1996. Areas for discussion included: current HAART regimen and dosing difficulties (in particular, cessation of treatment due to intolerance or side-effects); previous HAART regimen(s) (if applicable); participation in clinical trials (if applicable); understanding of drug resistance, CD4 count and viral load (with reference to assessment, monitoring and impact on prognosis), treatment side-effects and risk management strategies (regimen change, treatment cessation, treatment holidays); strategies for managing the impact of treatment on everyday life (work, socializing, sexual practice); sources of practical and emotional support; expectations for the future; assessment of the 'risks' of living with HAART (health, social, employment, relationships, sexual practice, disclosure, reinfection); understandings of the body with HIV; and use of HIV services. If not using HAART, interviewees were asked to talk about their expectations about using treatment, decisions to take it and understandings of side-effects and drug resistance.

Table 1 Age, year of HIV diagnosis and year commenced HAART for interviewees in Glasgow and London

	<i>Location</i>	<i>Age</i>	<i>Year of HIV diagnosis</i>	<i>Year commenced HAART</i>
Alan	Glasgow	34	2001	None
Ben	Glasgow	40	1997	HAART
Colin	Glasgow	28	2000	HAART
David	Glasgow	55	1998	None
Edward	Glasgow	32	2001	HAART
Frank	Glasgow	43	1998	HAART
George	Glasgow	40	1996	HAART
Henry	Glasgow	38	1995	HAART
Ian	Glasgow	37	1992	HAART
James	Glasgow	32	1999	None
Kevin	London	40	1994	HAART
Liam	London	55	1986	HAART
Michael	London	37	1998	HAART
Neil	London	52	1986	HAART
Oscar	London	48	1984	HAART
Perry	London	47	1992	HAART
Russell	London	33	1998	HAART
Stanley	London	42	1985	HAART
Timothy	London	30	1997	None
Tony	London	28	2000	HAART

Note: Names are pseudonyms.

Ethics

Interviewees were asked to provide written or e-mail consent once they had read an information sheet that described the study purpose and how their interview would be anonymized and used in the research. Ethical committee approval was granted from Glasgow Caledonian University Psychology Department, Glasgow Royal Infirmary University NHS Trust and UCL Hospitals Research Ethics Committee. During the interviews it was made clear to participants that they were under no obligation to answer particular questions and that at any time they were free to terminate the interview and withdraw from the study. Interviewee transcripts are identified by a pseudonym, location (Glasgow or London), age, ethnicity and year of diagnosis.

Analysis

Using constant comparison, themes were generated pertaining to the experience of considering or using HAART (Strauss and Corbin, 1998). The analysis of Glasgow and London interviews was combined because these did not suggest major differences between the locations in accounts of the experience of using HAART. Themes were justified with analytical memoranda. Analytical bias was addressed through transparent

documentation (NVIVO), justifying the viability of themes with reference to negative cases and team-based interpretive analysis (Popay and Williams, 1997; Silverman, 2000). Data presented in the following are identified with pseudonyms, location (London or Glasgow), age, year of HIV diagnosis and whether or not currently using HAART.

Findings

The findings are discussed in three parts. First, we provide an overview of how the interviewees accounted for aspects of the post-HAART situation including: general responses; using HIV clinics; the link between adherence and uncertainty; and social stigma. Second, we identify the several 'modes' of accounting related to different experiences of using HAART, illness and side-effects and personal engagements with uncertainty. Finally, we discuss 'technological horizon' as the main method used by patients to negotiate the uncertainties of the post-HAART situation.

The post-HAART situation for gay men with HIV

Consistent with recent published accounts, the interviewees referred to improved life expectations because of HAART (Trainor and Ezer, 2000; Lee et al., 2002). For example, this interviewee, Kevin, reflects on his experience of HIV diagnosis prior to the introduction of HAART:

when I was first diagnosed, like before, people with HIV, it was like, you didn't have a long life, you couldn't think that you would be alive in 10 years' time. Whereas now with everything that's happened . . . whereas before I don't think there was the option so, yes, it's not the end of the world. It's a hurdle. You've got to look at intelligently and think yes, I can continue to have a great life. (Kevin, London, 40, 1994, HAART)

Kevin acknowledges that the process of taking up HAART is not seamless, but that problems need to be set against the increase in life prospects. But it also seemed that life expectations were somewhat limited because of the uncertainties entailed in medical prognosis:

if I said to my doctor: 'What are my chances over the next five years', he would still probably say: 'Well they are reasonable for three years but after that can't really say.' And that's always been the same, the whole way through. (Neil, London, 52, 1986, HAART)

Neil indicates that formal prognosis has remained the same pre- and post-HAART. While the improved life prospects attributed to HAART are recognized, medicine itself is more circumspect. There is a difference then between how HAART is popularly constructed and what medical science will allow. Uncertainty is the important aspect of these different prognostic calculations. In the accounts of gay men with HIV, uncertainty is managed by drawing out the implied opportunity of HAART and not dwelling on the negative. In medical prognosis, uncertainty is managed as

a technical exercise of estimation based on the observed life chances of clinical cohorts. The challenge for gay men with HIV is dealing with both kinds of engagements with uncertainty. Perhaps as a result, interviewees had difficulties planning for the future:

I have to turn my life around really because one thing it does do which is I think very sad is you don't make any plans for the future. No long-term plans. Now you know, even at my age I'm sure if there is nothing wrong I would still want to buy a house, get a mortgage, do a bit of work over, do you know what I am saying but there is nothing, you are just existing. (Oscar, London, 48, 1984, HAART)

This example draws attention to the liminal or in-between quality of the post-HAART experience. When using HAART, imminent death recedes, but a future life is difficult to entertain.

In contrast with recent accounts of the post-HAART experience of uncertainty among people with HIV, the accounts in this study were marked by heterogeneity (Lee et al., 2002). Interviewees referred to various forms of engagement with aspects of HAART such as interpretations of blood tests used to monitor treatment, methods of self-care and their relationship with the prescribing clinician. For example, some interviewees constructed themselves as proactive, interested in influencing their doctors and in constructing effective communication:

R: I went on the drugs because I decided beforehand that if my viral load went over 100,000 or if my T-cell count went under 200 then it would've been time to start talking with my doctor about going on drugs or going on some regime.

I: What do you attribute your ability to be informed about treatments and being able to manage your own care like that?

R: I'm not sure really. It's just that, you know, when I found out I thought 'oh well, all right, we've got to deal with this' and the only way I can deal with it is by getting more knowledge about it. (Russell, London, 33, 1998, HAART)

However, other interviewees were less interested in actively shaping the clinical encounter, preferring to reduce their health care to a routine reliant on the professional expertise of the doctor:

I mean obviously I don't sort of read up about everything. It's things like you know I was reading in the Aids Update this morning that TB is on the rise. So things like that I find more interesting, than medication. I just leave that to [HIV Clinician]. He'll choose what combination he wants me on. I'm quite happy as I say I trust [HIV Clinician] to not kill me. [Laughs] (Ian, Glasgow, 37, 1992, HAART)

The contrast between these forms of engagement with the practice of HIV prescribing is important for conceptualizing HIV care. The accounts suggest that HIV care needs to be able to accommodate both a traditional division of expertise between the clinician and the patient and the participatory 'expert patient' model.

Previous research has also suggested that the rigours and uncertainties of HAART may undermine treatment compliance (Lee et al., 2002). In general, the interviewees in our study did not report current difficulties with taking their drugs nor was dosing connected in the accounts with uncertainty. Discussion of adherence reflected the need to build pill taking into everyday life and find support to do so:

Well I was put into triple therapy immediately, quite heavy and I had to take lots of other stuff as well, massive doses of antibiotics for about two years, all sorts of extra . . . all sorts of extra things, you know, like prophylactics and stuff like that and at first it was quite hard but again the people at the clinic were very good, very supportive, and I was quite impressed . . . there were times when I was taking over 30 tablets and some of them had to be taken on an empty stomach, some of them had to be taken with food, and it was a very, very oppressive regime. This one is less . . . there's still a lot of tablets but it's a lot less and there's only one of them now that I take first thing in the morning that requires an empty stomach. The other ones I can eat, not eat, drink. (Ben, Glasgow, 40, 1997, HAART)

Some aspects of the post-HAART situation for gay men resemble pre-HAART. As established in other recent research, the interviewees expressed enduring concerns about HIV-related stigma in health care, in the gay community and in sexual practice (Dodds et al., 2004). In particular, the interviewees were concerned about changes in appearance that might signal HIV status, disclosing HIV serostatus to work colleagues, family members and to sexual partners. An additional focus for interviewees was the risk of HIV transmission to sexual partners. Despite effective treatments therefore, gay men with HIV still experience significant problems of identity and social interaction connected with their serostatus.

Different modes of the post-HAART experience

A key part of the research involved asking interviewees what they thought and felt about their experience of considering or using HAART. This achieved a deeper, heterogeneous analysis of engagements with uncertainty. In an effort to analyse the complexity of these accounts, we grouped them into different 'modes' of the post-HAART experience. The first mode comprises the 'before treatment' accounts of those interviewees who had not yet used HAART. The remaining modes comprise 'after treatment' accounts: 'good health'; 'post-illness'; and 'loss of confidence'. We do not assert that these 'after treatment' modes are fixed in time or mutually exclusive. Nor do we have a sense of the numbers of patients for whom each mode might be relevant, a point we will return to in the discussion in connection with the evaluation and monitoring of HAART in the clinic. But, the different modes attest to the diversity of the post-HAART situation for gay men with HIV and the emerging challenges for HIV health care.

In the 'before treatment' mode, interviewees who had not yet taken HAART had a general understanding of it and some concerns. They

described treatment by referring to what they had gleaned from treatment information sources, carers and gay men in their social networks using it. For example, interviewees admitted their lack of knowledge and involvement with treatment: 'I don't know an awful lot about it. I mean I've not really got involved in all that sort of side of things because at the moment I'm healthy, I see myself as healthy' (James, Glasgow, 32, 1999, never used HAART). From a position of healthiness, James constructs HAART as distant and less relevant.

Interviewees in the 'before treatment' mode had an idealized understanding of how HAART works:

Well, from what I understand about them, it's now different courses for people depending on what kind of strain you've got and how advanced it is or how fast it's coming on you . . . what I understand it can be as little as two tablets to be taken each day. And as you react to the tablets they'll change them and change the doses until they've got the one that suits you . . . I just take it when it's my turn to need them then I'll just obviously leave that to the professionals. (Alan, Glasgow, 34, 2001, never used HAART)

In this example, Alan brings together an idealized vision of HAART and a traditional notion of the doctor/patient relationship. The account reflects awareness that HAART is tailored to personal circumstances through the guidance of experts. It is a vision of HAART that invests trust in the technology and HIV prescribing. Interviewees in the pre-treatment mode were also aware that using HAART was not easy: 'I'm not worried, but I think the fact that you have to keep to a regime the rest of your life is kind of daunting' (David, Glasgow, 55, 1998, never used HAART). In the pre-treatment mode of accounting, HAART emerges as a technologized process and a significant consideration, but not overly problematic.

The other identified modes of the HAART experience were constructed by interviewees using HAART. The good health accounts were made by interviewees who found HAART unproblematic. These interviewees reported no serious illness related to either HIV or side-effects associated with treatment:

I usually feel quite well because, although there's been a lot of permanent damage done, and some significant changes in my appearance and body, the results have been fantastic . . . there's been a couple of hitches on the way, but it's mainly been consistently good, so the results are fine. (Ben, Glasgow, 40, 1997, HAART)

. . . had no real problems, skin problems occasionally, diarrhoea, occasional headaches . . . but otherwise the therapy's been brilliant. (Kevin, London, 40, 1994, HAART)

In these accounts, HAART side-effects are minor, temporary and manageable. HAART itself is seen as reliable and effective. Uncertainties do not intrude. However, in some cases, the interviewees also preferred to not

reflect on HAART-related uncertainties too much, adopting a stoic approach:

Half the battle I think is in your mind too. I mean it's a terminal disease. It's gonna get me eventually . . . but you can't linger on it. I feel good today. You're gonna live good today. (Colin, Glasgow, 28, 2000, HAART)

it's not something I want to forget, but it's not something I want in the forefront all the time . . . I don't dwell on it. I think there was a time where obviously I dwelt on it. But now it's like fine, just get on with it . . . I think that really you should talk to people . . . different types of terminal illnesses so that you see other things, and learn other things and it's not just sort of HIV. (Kevin, London, 40, 1994, HAART)

These latter examples of accounts of good health indicate the presence of some uncertainty about the future. But this uncertainty is managed by not focusing on HIV or treatment prospects and by relativizing the experience with that of other chronic illness. A traditional interpretation of such cognitive strategies might be to think about the function of social comparison or denial. However, these ways of accounting may also reflect the active management of uncertainty.

A further contrasting set of accounts was derived from interviews with gay men who had experienced serious illness and side-effects. These events occurred prior to, or in parallel with, the introduction of HAART in the mid to late 1990s. They were related to HAART side-effects and intolerance. These accounts expressed the strain of the stamina required to use HAART and emotional fragility:

it's six of one or half a dozen of the other. It is better in one area but there is a downside to it and side-effects and various other things like muscle wastage and cramps and falling. You know my legs gave way and, yes, there is an up side. But there is also a down side. It's not smooth sailing believe you me. It isn't. But I feel if I didn't go on treatment it would have been downhill much faster. At least this way there is sort of like – I suppose it's like a leaking tap. You put a tourniquet around it and you are hoping it won't burst out, but the tourniquet will prevent the water from gushing out for as long as you can. (Oscar, London, 48, 1984, HAART)

Oscar's account provides a different picture of the HAART experience. In place of the unreserved endorsement of HIV treatment, there is ambivalence about the experience and a sense of the strain of managing mind and body in the long term. The 'leaking tap' metaphor works to underline the temporary quality of HAART and its meaning in these accounts of something makeshift until such time as a better solution can be found.

Another set of accounts suggested a 'loss of confidence' in using HAART. Interviewees using this mode of accounting referred to experiences with serious illness and side-effects and expressed distress. In this mode, HAART and the related caring was seen to be failing:

other things have happened and so I have a huge gum disease that can be, but maybe it is not linked to HIV . . . I've lost many, many teeth, and I'm losing them all. It's just a matter of time and now I don't have confidence any more . . . doctors are always in a hurry. They're always in a hurry. I never arrived late for an appointment. Many times even if the patient before me didn't come they're in a hurry . . . you know they never have time for you. (Perry, London, 47, 1992, HAART)

In this example, Perry expresses a loss of faith in both treatment and HIV care. Questions about the effectiveness of HAART led interviewees to challenge the idea that HAART was treatment as such or that its effectiveness could be sustained in the long term:

To call it a treatment is a real misnomer because what happens is the press gets hold of it and they start writing articles about new treatments and they're not treatments at all because treatment I think infers that it's a cure [and that] HIV has now become a manageable thing. HIV therapies aren't either of those things. At the moment it's a short stop thing that in most cases has awful side-effects, some in the short term and some in the long term that people don't even know yet . . . People were saying these are fine. You might get diarrhoea. A bit of nausea or whatever or something, but they're all manageable, there's nothing life-threatening and of course it's not the case. The fact that kidneys have got holes in them and leak because of DDI. I was prescribed DDI and no-one knew such a thing would happen . . . I don't think either it's a treatment or it's a management of HIV. A short stop-gap to try and give you a bit of extra time in the hope that newer and better drugs will come along that will be able to treat it or manage it long term or maybe have a cure. (Stanley, London, 42, 1985, HAART)

I'm like 10 years down the line and you know . . . my viral load is undetectable, and it has been for a couple of years now and I just think you know the bubble's going to burst at some point. I suppose it's quite, is it pessimistic? You know, to think that way but you think, how long can you go? (Ian, Glasgow, 37, 1992, HAART)

These 'loss of confidence' accounts contrast with the other modes of accounting. In place of a reified notion of HAART we see more fragile accounts incorporating the distress related to increasingly uncertain futures. From their points of view, HIV care was insufficient and the public representation of HAART was misleading.

Managing uncertainty and the value of technological horizon

As we have discussed, the post-HAART situation implies the challenge of combining the use of treatment, life expectations and uncertainty. Uncertainty is met by forming self-management strategies in connection with the sense of unfolding technology and therefore unfolding futures. With reference to the innovative health technologies and sociology of expectations literature, we conceptualize HIV treatment reflexivity as 'technological horizon' (Webster, 2002; Brown and Michael, 2003). Technological horizon

is comprised of the unfolding quality of the changes and developments that underpin HAART, a sense of the life course interconnected with HAART and the uncertainties entailed in using it. HAART itself was seen as more than a definite object or practice. The pills themselves, blood tests and clinical routines were crucial to the management of effective treatment and central to experience. But the implications of these elements of HAART were interpreted in terms of the idea of the ongoing innovation of HAART and therefore the implications for biographical time. Along with the day-to-day tasks of drug dosing and regular attendance at clinics for blood tests, patients were focused on optimizing the positive and avoiding the negative aspects of HAART through this concept of technological horizon. The interviewees did not necessarily see themselves as passive in connection with uncertainty. In addition, the everyday, personalized strategies of uncertainty management, framed by technological horizon, contrast with the more general, ideological hope that sustains biomedical enterprise. Technological horizon was relevant to interviewees with differing engagements with HAART, illness experiences and side-effects. Interviewees referred to preserving treatment for later, carefully choosing treatment options and treatment changes and looking forward to technical advances in HAART.

The following extracts demonstrate how interviewees considered that HIV treatment was in part a function of improving technologies and time:

my actual medical care the whole way through, I mean the 17, 20 years, that I've been HIV has been exceptionally good in terms of my medical care. And by that I mean whenever there has been something wrong with me, things have moved quickly. Whatever treatments were available I had them . . . as the technology has developed I had access to them. (Neil, London, 52, 1986, HAART)

Neil's accounts summarize the sense of shifting technological horizon. Similarly, Ben refers to the timeliness of HAART in his early experience, but later a sense of HAART mistimed:

I've been lucky I think because if I'd got sick even three years before I did, I would be dead. When I was in hospital, the main doctor, told [Participant's partner] I had two years to live maximum. And then he said 'Oh actually, make that one', because they really did not know how to deal with toxo, they didn't know how to manage HIV so well . . . there was a time when I realized I was running out of options and there was the beginning of discussion and concern about changing therapy or hitting hard too soon, kind of thing, and I suppose there was a grain of resentment there somewhere when I thought 'Well they could have kept me on it, you know, and now I'm in a position where . . . what am I going to do if what I'm on currently stops working?' But I think that's the way it had to go, really. I'm quite aware that I am an experiment in progress, but there's been good results. (Ben, Glasgow, 40, 1997, HAART)

Ben's account captures a roller-coaster quality of the post-HAART experience. Lived experience is embedded in both current and future technological developments. In the next example, Russell discusses how he

aimed to avoid a class of anti-HIV drugs because of their reputed side-effects. He also spoke of delaying the commencement of HAART as a way of extending time and allowing for technical improvements:

R: I decided when I was doing my research that I wanted to stay away from protease inhibitors if I could help it in the first instance, and then save them for later on down the track if I needed another type of drug to fall back on at some stage.

I: Why did you want to save them for later?

R: The main thing was the side-effects of protease inhibitors and from what I saw and what I read and talking with other friends who were on treatment that they were the ones that they felt gave them the worst side-effects and also impinged on . . . eating an hour beforehand, not drinking for [an] hour afterwards and all those sort of dietary restrictions which would be – not impossible, but a bit trickier with me and wanting to continue working full time. (Russell, London, 33, 1998, HAART)

Russell's example demonstrates how knowledge about aspects of HAART is used to develop a treatment strategy that will capitalize on innovation and further biographical time. In the next example, Stanley discusses a strategy of taking breaks from treatment to moderate side-effects:

I'm well aware of the risks that are involved . . . to keep on top of those risks I have myself monitored more often and make sure I know the results and what have you. And when the time comes we can go back on. But in the meantime we always try and find a solution to whatever's caused the problem and I've had to go off them. I was having breaks from therapy long before it was sort of accepted. It was a definite no-no and other people including friends and other doctors, apart from my main doctor, were very sceptical and didn't think it was a good idea. But as I say I'm very fortunate that Doctor X is brilliant. He really is. We do work as a team and it's never been a problem. He always tells me about stuff I don't know and it's never been a problem.

I: So would you say that you work together to come up with solutions?

R: Yes, yes.

I: And you obviously read material and do research outside what . . .

R: I'm not obsessed by it, but if there's something new coming up I'll have a read. I may not necessarily remember it all but at least I've had some background. If something's wrong with me that I'm not familiar with I'll go on the net and find out or read something about it. (Stanley, London, 42, 1985, HAART)

Stanley's account makes reference to staying abreast of innovations. Side-effects are therefore managed by altering treatment, but also in light of possible future developments. In the next example, Ian discusses lypodystrophy of the face and considers a change in treatment:

Well . . . I think I look like Skeletor. My face is quite sunken, but that's the only thing that I can see that is different. I mean as I say I've always been quite slim. But now I'm quite gaunt and that that gets me down a bit, to be honest. But again I'm not that fazed that I change a regime that's working, just because I

don't like the way I look, you know. But, unless they find something to combat that, I cannot see anyway around that. (Ian, Glasgow, 37, 1992, HAART)

Ian's account expresses an engagement with technological horizon in connection with the management of side-effects. His strategy is to keep his current regime until such time as other options are available. The prospect of failing treatment required a different kind of approach to uncertainty. In this context, interviewees turned back to a traditional sense of uncertainty as fate:

I mean what's that expression: 'What doesn't kill you, makes you stronger' sort o' thing. You know so what I'm saying there is that if you don't have any control over it, why bother worrying about it? Does that make sense? . . . I don't know how I'd feel if they actually turned around and said: 'Listen all your medication has failed and you've got five minutes to live.' I think I would (laughs) drop down at his feet maybe but until that happens I cannot really say . . . I don't worry about it. (Ian, Glasgow, 37, 1992, HAART)

In this example, Ian captures a sense of the limits to required agency for gay men with HIV. For him, recognizing what he is not able to change is a source of relief. Similarly, Henry also suggests a way of dealing with uncertainty beyond management: 'Time is the factor on a lot of HIV people. And if anything, time gives you hope as well, believe it or not . . . I deal with that bridge when I cross it' (Henry, Glasgow, 38, 1995, HAART). Henry relies on a metaphor of a journey to help construct a way of living with uncertainty. 'Crossing the bridge' is a kind of denial of agency, opening the narrator up to fate, but it is also a source of solace, a way of living with the uncontrollable.

Discussion

This article has provided a description of experiences of living with HAART from the points of view of gay men in Glasgow and London. Instead of a top-down view of how the advent of HAART impacts on health and well-being, we have aimed to use the accounts of gay men with HIV to question some of the assumptions of the post-HAART ordering of knowledge about living with HAART and HIV care.

In general there is a need to guard against globalizing accounts of the post-HAART situation, common in media and policy and, perhaps, HIV care. The interviewees expressed tempered hope about HAART, recognizing its benefits and dangers. Unlike previous research, uncertainty itself did not appear to undermine drug dosing (Lee et al., 2002). Some patients struggled with the negative aspects of treatment such as intolerance and side-effects, the emotional impact of uncertainty and the ongoing problems of social interaction connected with HIV positive serostatus. These are familiar challenges for people with HIV that can be traced back to the beginning of the epidemic (Herdt, 2001). Uncertainty, and the social

challenges of HIV infection in particular, are themes that have not been erased because of HAART. Instead, the advent and development of HAART intersects with uncertainty and identity in complex ways.

Our analysis also suggests that diversity among gay men using treatment characterizes the post-HAART situation. For example, some patients want to be actively involved in their HIV care, in keeping with the focus on the relationship or partnership-centred HIV clinical care (Gerbert et al., 2000; Race, 2001b). Active involvement in treatment is also reflective of the notion that people affected by HIV have resisted and re-deployed medical power, for example by increasing access to treatment and user involvement in clinical research and practice (Epstein, 1996). But the analysis also suggests that other HAART users prefer a more traditional relationship with the prescribing clinician, leaving the medical practitioner to make the best decisions. Such diversity of approaches to HAART suggests that the resistance of medical power in the post-HAART situation is not universal. Instead, practices of self-regulation appear more individualized and reflective of strategic resistance to, and/or co-option of, traditional forms of medical practice. It may be that as the capacities of HIV medicine develop, collective resistance becomes less relevant. It is also the case that health care in general has become more individualizing, reflected in UK policy frameworks that focus on the expert patient (DOH, 2001). Such individualization and the related reorganization of engagements with medical power is also in keeping with the notion of 'precarious freedom' discussed by theorists of the late modern social order (Beck and Beck-Gernsheim, 2002; Lash, 2002) or of HIV treatment in particular (Stephenson, 2003). In addition, as noted by Epstein (2000), patient involvement in HIV clinical practice and research can become reflective of social divisions to do with class and ethnicity. Our analysis suggests nuanced engagements with medical power, reflecting technological innovations and changes in health care subjectivity, structured by social differences such as educational background and ethnicity.

This article focused on the different modes of accounting for life with HAART (before treatment; good health; post-illness; loss of confidence) as a way of exploring the interplay of use of HAART, uncertainty and expectations. The analysis raised questions for further research, HIV care and HIV prevention.

There is a need for more information about individual therapeutic responses to HAART. Our current picture of the effectiveness of HAART is limited to global mortality statistics and clinical trials data (<http://www.bhiva.org/guidelines/2005/HIV/HIV05frameset.html>, 1 December 2005). Such data suggest that the 'good health' mode of experience may be the most prevalent. But as our research suggests, global statistics tell part of the story and may mask marginal experiences with HAART. In particular, we know little about the extent of the other 'post-illness' and 'loss of confidence' modes of the HAART experience and their place in clinical practice.

These modes may well be statistically small, generational and indeed reducing as HAART improves. But we need to be more confident that this is the case.

The different modes of the HAART experience discussed in this article suggest the specific psychosocial support needs of different people with HIV. The 'post-illness' and 'loss of confidence' groups may need kinds of support very different to the needs of those without serious illness or side-effects. Other researchers have suggested high levels of psychiatric morbidity among gay men with HIV using HAART (McNaught and Spicer, 2000). The fragility and loss of confidence expressed by some of the interviewees indicate emotional distress. The situation may be especially difficult for such patients as they comprise small groups and therefore may not be the main focus for HIV care. In addition, the interviews provide the basis for an approach to psychosocial care grounded in the methods and strategies used by gay men with HIV themselves. Recent work on self-care has adopted a deficit model and thereby has identified a role for psychosocial interventions such as cognitive behaviour modification (Kalichman et al., 1998). Some gay men may profit from such interventions. But we argue that interventions may be improved by understanding the different ways that people with HIV approach uncertainty.

The prevention needs of gay men with HIV may also vary depending on how they engage with HAART and their preferences for managing uncertainty. For example, the HIV prevention concerns of HIV positive gay men not using HAART or in good health, may be different to those patients who have had serious illness and side-effects. As with psychosocial care, practitioners need to be sensitized to the HIV prevention needs of different gay men with HIV. A key concept in HIV prevention research has been the idea of treatment optimism, derived from the health belief model, and its association with self-reported anal sex without condoms (International Collaboration on HIV Optimism, 2003). The accounts described in this article suggest that the notion of treatment optimism may be somewhat simplistic. HIV prevention researchers need to engage with the idea that gay men with HIV are not all the same in terms of how they engage with HAART and their experiences with it.

A key contribution of this article is the account of how people living with HAART use the idea of technological horizon to frame their engagements with uncertainty. Alongside the generalized idea of hope, and the necessary daily drug dosing and treatment monitoring, through the idea of technological horizon there is also scope for an active engagement with the uncertainties of the post-HAART situation. Patients spoke of delaying HAART, managing change and maximizing the benefit of technical advances. These strategies mirror how prescribing clinicians manage HAART on an individual basis. Current clinical guidance uses categories that resemble the accounts discussed in this study, including: when to treat; and when to change treatment (<http://www.bhiva.org/guidelines/2005/HIV/>

HIV05frameset.html, 1 December 2005). Research has come to focus on the doctor/patient relationship in HIV treatment as a focus for intervention (Gerbert et al., 2004) and as an innovation of medico-social relations specific to the uncertainties of the post-HAART situation (Race, 2001b). We suggest that the idea of technological horizon is the organizing discourse of the HIV treatment partnership. We suggest then that different forms of engagement with prescribing can be framed by this idea of technological horizon because it provides a way for both patients and clinicians to manage post-HAART uncertainties.

A kind of post-HAART fatalism also emerged as a way of defining the limits of personal responsibility. Fatalism is often characterized as a failure of the reflexive self, as a kind of giving up. In contrast, we argue that fate has value for patients because it provides a freedom to exist without blame. Chronic illness self-management discourse is often critiqued because it mobilizes moral judgement of those who are seen to fail to act to care for themselves in a responsible manner (Galvin, 2002). In this discourse, fatalism is regarded as a kind of denial or failure of reflexivity. We agree that chronic illness discourse is overly blaming, particularly as it seems to us that refusing reflexivity may also be an act of freedom. People with HIV need to be free to settle on fatalism as a way of existing with the limits of technological innovation in the treatment of HIV.

Note

1. Personal communication with Dr Jane Anderson, Barts and the London Hospitals Trust (2004). Dr Anderson suggested that the term 'post-HAART' was used in clinical practice.

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