"I will start treatment when I think the time is right": HIV-positive gay men talk about their decision not to access antiretroviral therapy

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“I will start treatment when I think the time is right”: HIV-infected gay men talk about their non-uptake of antiretroviral therapy

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Abstract

In a qualitative study, 20 HIV-infected Australian gay men were interviewed about their non-uptake of antiretroviral drug therapy. The main reasons given for not accessing therapy were fear of side effects; fear of long-term damage to body organs; the inconvenience of the treatment regimens; belief that the regimen’s demands would be a threat to morale; and belief that there was no reason to start therapy in the absence of AIDS-related symptoms. Actions taken by the men to monitor and maintain their health included seeing a doctor regularly; having regular T-cell and viral load tests; and trying to maintain a positive outlook by not letting HIV/AIDS “take over” their lives. Almost half the men considered they had been subjected to unreasonable pressure to access therapy and there was considerable pride at having resisted this pressure. The findings suggest that the men were content to go along with the biomedical model for managing HIV/AIDS on all matters other than the question of if and when to access therapy. They also suggest that underlying the men’s dissent from the biomedical model was a different mode of thinking than is required by the model: contrary to the model’s demands, the men focused strongly on factors close to the “here and now” of immediate experience. The practical implications of the findings are explored.
“I will start treatment when I think the time is right”: HIV-infected gay men talk about their non-uptake of antiretroviral therapy

Introduction

Treatment for people infected with HIV has been greatly improved by the introduction of combination therapy with antiretroviral drugs (Moore & Chaisson, 1999; Vella & Mildvan, 1998). Current guidelines favour early intervention, with the International AIDS Society-USA panel recommending that therapy should commence in any patient with a plasma HIV-1 RNA level greater than 5,000 to 10,000 copies/mL (Carpenter et al., 1998). Despite these recommendations, it seems that appreciable numbers of people with HIV are still not accessing antiretroviral therapy. In Australia, the site of the present research, for instance, it is estimated that between 40% and 45% of people who have tested HIV-positive are not on antiretroviral therapy (Goddard & Bartos, 1998).

Why might people with HIV decide not to take up antiretroviral therapy even at a time when the benefits are widely attested and heavily publicised? Most published studies on non-uptake have reported data collected in the period before the successes of combination therapy became well-known, so that the current applicability of their findings remains unclear. Demas et al. (1998) and Mostashari et al. (1998), for example, collected their data during 1993-95. Among the reasons for non-uptake identified by these authors were lack of confidence in the efficacy of the drugs available and concern about their side effects.

More recent data (collected in 1998) have been reported by Gold, Hinchy, and Batrouney (in press). In that study, HIV-infected Australians not accessing antiretroviral therapy were asked questions regarding their health, any previous use of antiretroviral drugs, and the extent to which
they were monitoring their T-cell counts and viral loads. In addition, those participants who had considered going on antiretroviral treatment, but then decided not to do so, were given a list of possible reasons for their decision, and asked to indicate the extent to which each had played a role in their thinking. It was found that the great majority of participants were having regular T-cell and viral load tests, and that most had considered accessing antiretroviral therapy. Reasons for not starting therapy did not differ greatly at different stages of HIV disease. The most common individual reason was fear of side effects. Other important themes that emerged included distrust of conventional medical approaches to treatment, practical problems associated with taking antiretroviral drugs (such as anticipated difficulty in complying with demanding treatment regimens), and unpleasant thoughts that being on therapy would evoke (such as the constant reminder that one has HIV/AIDS).

Gold et al.’s (in press) study was designed to produce data suitable for, and to obtain a sample large enough to permit, detailed quantitative analyses. These requirements constrained the method of data collection; a very focused and highly structured questionnaire, easy to complete since participants simply had to insert numbers in the appropriate spaces, was employed. While this approach was suited to the study’s aims, it also had disadvantages. In the interests of brevity, some matters of interest – the extent to which respondents felt they had been unreasonably pressured to change their decision not to access therapy, for example – were not covered. There was no opportunity to ask follow-up questions about several matters that emerged as central: it was not possible to determine, for instance, just which side effects respondents were most concerned about and the source of their information about these side effects. Most importantly, since participants did not have the opportunity to tell their stories in their own words, their individual stories and voices – their personal interpretations, phrasing, emphases, and emotions – were lost.
The present study was intended to complement Gold et al.’s work by addressing the same issue, but using a contrasting methodology: an in-depth, open-ended interview with just a small sample of HIV-infected people not accessing antiretroviral therapy. The aim was to employ qualitative rather than quantitative analyses, and thus to preserve some of the richness inherent in individual accounts.

**Method**

**Sample**

Since HIV/AIDS in Australia is primarily a disease of gay and bisexual men living in Sydney and Melbourne (AIDS/Infectious Diseases Branch, New South Wales Health Department, 1998; Infectious Diseases Unit, Victorian Department of Human Services, 1998; National Centre in HIV Epidemiology & Clinical Research, 1999), the sample was recruited from this population. A convenience sample was used. One advertisement was placed in a newspaper serving the gay community in each of these two cities. The advertisement gave the purpose of the study as simply being to find out why many HIV-positive Australians had not decided to access antiretroviral therapy. The first 20 men to respond to the advertisements, 6 from Melbourne and 14 from Sydney, were included in the sample.

The ages of the men ranged from 22 to 49 years and all considered themselves to be gay. The length of time that they had known themselves to be HIV-positive ranged from 1 year to 16 years. Four had experienced an AIDS-defining illness. Ten were no longer in paid employment (or were only working sporadically) and were receiving the government disability support pension. All but two had had T-cell and viral load tests, although one could not remember his most recent T-cell count and two could not remember their most recent viral load result. Among those who did
remember, the most recent T-cell count ranged from 103 to 980 and the most recent viral load ranged from 3,000 to 447,600. Of those who knew their viral load, all but one should have been on antiretroviral therapy according to the criteria of Carpenter et al. (1998). Four had been prescribed antiretroviral drugs in the past (although one of these had tried the drugs only very briefly). It is seen that a broad range of HIV illness was represented in the sample.

**Procedure**

Rapport was established with each man during a preliminary telephone call and then at a face-to-face meeting immediately prior to the interview. It was emphasised that we were not “treatments police,” out to promote antiretroviral therapy, and this seemed to reassure the men that they could speak freely. All interviews were conducted individually, over a period of about one month towards the end of 1998. The first author acted as interviewer; this author has conducted research relating to HIV/AIDS with the gay community over the last dozen years, and is well-known in the community. In Melbourne, the interviews took place in the home of either the interviewer or the participant; in Sydney, they took place in a quiet room at a hotel in the heart of the main gay precinct. Interviews ranged from 40 minutes to an hour in length and were audiotaped. Each participant was paid $AUS30 for his assistance.

Informed consent for participation was obtained at the start of the interview. The participant was then reminded of the purpose of the study and invited simply to “tell his story” in his own words. The interviewer was an attentive but largely passive participant in the conversation, speaking as little as possible, and limiting himself to general, open-ended questions, and requests for expansion or clarification. The main focus of each interview was the participant’s reasons for not accessing antiretroviral therapy, but the interviewer ensured that other questions of
interest – such as those, mentioned above, which had been left unexplored in Gold et al.’s (in press) study – were also covered.

Analysis

All interviews were professionally transcribed and checked for accuracy by the first author. The first author then immersed himself in the data by reading all the transcripts a number of times. A computer-assisted package for coding and analysis of qualitative data was not used; rather, the interviews were coded manually for major themes. The data were cross-coded by the second author, who read through the transcripts and independently developed his own coding system. The two coding systems were then compared. The codes retained in the final system were those that could be defended in the researcher sessions held at regular intervals during the ongoing analysis. Of particular value to the process was the fact that different perspectives were brought to bear, with one of us being a cognitive psychologist and the other a qualitative researcher trained in medicine and the social sciences. For both researchers, themes were inductively developed from specific phenomena in the data in accordance with the principles of grounded theory (Glaser & Strauss, 1967). In turn, these themes directed the search for additional concepts in the general literature that could help clarify the analysis and contribute to an overarching framework for conceptualising the findings in their entirety (Layder, 1993).

Results

The themes that emerged from the men’s accounts had to do with three broad areas: their reasons for deciding not to take up therapy, the actions they were taking to address their condition, and the
excessive pressure to access treatments they felt they had experienced. We present the comments relating to these areas in this order. All names used with the interview extracts are fictional.

Reasons for non-uptake of antiretroviral therapy

All the men in the sample accepted that AIDS-related illness is caused by infection with HIV, which acts by attacking and weakening the immune system. Further, they were all reasonably well-informed about current treatments for HIV/AIDS. All were aware that new antiretroviral drugs had become available in recent years – most were able to name at least one of these drugs – and all knew that they were claimed to provide greatly improved treatment. All were aware that the conventional medical wisdom was to begin therapy early. They had obtained their information through contact with friends, doctors, and community organisations, and through reading (albeit irregularly) any of several publications directed at Australians living with HIV/AIDS.

Despite being well-informed about the new treatments, none of the men was prepared to access them, at least at this time. Four of the men rejected antiretroviral therapy entirely; they were adamant that they would never access therapy whatever happened. The rest thought that they might commence therapy eventually, but intended to postpone doing so as long as possible. Five main reasons featured in the men’s thinking.

Side effects. The great majority (85%) identified fear of side effects as among the most important of their reasons for not accessing therapy. Of those who did this, three had personal experience of side effects. The rest based their judgments on the experiences of friends who had used antiretroviral drugs.
Warren (37 years old, HIV-positive 14 years): I also know people where the medications have made them incredibly ill. I have two friends specifically, who have taken them, both have taken themselves off all the medications, they’ve had enough...About three or four years ago, a friend had self-delivered and...he left a note saying why he took his life, he just couldn’t handle the pain that one of the medications was causing. And just recently another friend, he’s got the same pain in his feet from the medication. And it’s one of the medications they want me to go on.

The men seemed most concerned about side effects that would disrupt their day-to-day functioning. Among these effects, they seemed to particularly dread those associated with becoming “dirty” or “soiled”; the effects mentioned most commonly were diarrhea and vomiting. Side effects that did not fall into this category seemed of rather less concern. For example, although most of the men knew that lipodystrophy (repositioning of body fat) was a side effect – much had been written about it in the gay press during the period before the study – this was cited appreciably less often. When the men talked about the possibility of experiencing diarrhea or vomiting they spoke with considerable vehemence and used graphic imagery, attesting to the horror with which they regarded these effects.

Matthew (33 years old, HIV-positive 3 years): Vomiting, diarrhea, like, you didn’t even know it was going to happen. I could be sitting here and just vomit without even any warning. And the same with the diarrhea, you know. If you’re sitting in a pub and then it just happens, it’s like, well, you know, I’m in here, I live all the way over there, how do you get home with dirty trousers on? You can’t sit in a cab or bus or whatever.
The men felt that the official medical discourse tends to trivialise side effects. Indeed, some considered the very term “side effects” to be inappropriate, since it inherently downplays the status of such effects, relegating them to merely peripheral events. Rather than divide the results of therapy into “main effects” and “side effects,” the men tended to contrast the increased years of life which, they freely acknowledged, treatment might bring, with the decreased quality of life that side effects would cause. In their view, the latter was of greater consequence than the former, rather than the other way round.

Brian (47 years old, HIV-positive 15 years): I just think, to me a lot of it’s been trivialised. That’s my way of thinking. What’s classified as minor? The idea of living (as someone who’s headache-prone anyway), with chronic nausea and headache. That really is to me a major thing about quality of life.

Patrick (24 years old, HIV-positive 1 year): I’d just rather have those 5 years of good living than 15 years of shit.

Yet another indication of the importance of side effects is the fact that the three men who had personally experienced them were among the four who utterly refused even to consider the idea of accessing therapy. These men were absolutely determined never to suffer such side effects again.

Interviewer: Have you ever considered taking up the antiretrovirals again?
Bill (49 years old, HIV-positive 13 years): No, no....
Interviewer: You had a bad experience?
Bill: Yeah. And no, I would never...
Interviewer: You would never go back on them again?
Bill: No.

Interviewer: What happens if your, let’s assume that your viral load goes up, and your T-cell count comes down. And your doctor says...it’s time for us to do something else, in the way of antiretrovirals?

Bill: No.

Interviewer: The answer would be no?

Bill: No.

Interviewer: OK.

Bill: I will not take any more drugs and if I do get sick I’m not to go on any life-support system whatsoever.

Toxicity. Half the men referred to the toxicity of antiretroviral drugs as an important reason for not taking up antiretroviral therapy. This too had to do with side effects, but this time much longer-term ones. The men’s argument was that antiretroviral drugs are not specific enough to attack only HIV; rather, they may also cause long-term damage to organs such as liver, kidneys, and pancreas. In some cases, the men were quite sure that such damage is caused by the drugs; usually, this judgment derived from the experiences of friends on antiretroviral therapy.

George (43 years old, HIV-positive 16 years): I’ve seen some friends that have gone on to antivirals and just, choo [lets hand drop like a stone]. Like I lost a friend last week who’s been HIV as long as I have, and he went on to antivirals about 3 months ago....My main objection would be, well, they’re bloody toxic....They do attack everything, you know, not just, I mean they do build up your immune system...but...they hit everything else as well.
At best, the men concerned about toxicity considered that the full long-term effects of the drugs are as yet unknown.

Peter (41 years old, HIV-positive 16 months):  The way that the drugs are metabolised. You know, through the liver, through liver, kidneys. I mean, over a period of time we don’t know how toxic they are to the liver....I mean I don’t want 20 years of being on combination therapy and having a stuffed liver, because we don’t know at this stage how toxic these are going to be long term.

Once again, the men felt that the toxic effects of the drugs were too important to be referred to merely as “side effects.”

Brad (39 years old, HIV-positive 5 years):  [W]hat is the point in me adding harmful chemicals, or potentially harmful, well, harmful in the sense they can make your kidneys pack up, they can give you jaundice, they can give you pancreatitis, all kinds of different things. I don’t consider those to be side effects, I consider them to be direct, primary effects of the chemicals which, they were illnesses which weren’t there before the patient started taking those chemicals, so I don’t see them as side effects.

Inconvenience. Almost half the men identified the inconvenience of the treatment regimens as an important reason for not going on antiretroviral therapy. Three of these men had personal experience of the difficulty of complying with the regimens; the rest based their assessment on the experience of friends.
Matthew (33 years old, HIV-positive 3 years): Just the fact that they had to be taken 8 hours apart and, you know, if you were going out and didn’t know how long you were going to be, you had to have a pocket full of pills, and you know, you had to take them while you were out. And some of them had to be taken with food at midnight. Well who feels like eating at midnight, you know? Especially if you’ve been in bed for 3 hours, you don’t want to wake up and sit down and have a meal and drop half a dozen pills or whatever it is, and then go back to sleep.

The men’s concern about the inconvenience involved was heightened by their belief that they would have to comply with the demands of the regimens for the rest of their life.

Murray (35 years old, HIV-positive 5 years): For me, it’s an inconvenience for life. I mean, if you have to keep taking these, if you can’t miss a dosage, to me it’s a life-term sentence of taking pills, before meals, after meals, crushing pills.

The men took into account their own particular personalities and lifestyles in deciding that they would have trouble complying with the regimens.

David (34 years old, HIV-positive 13 years): I lead a hectic life, I’m very absent-minded, and I’m sure I would probably forget doses, and have trouble, especially if it wasn’t a simple routine, like once in the morning and once at night. If there were drug routines that fell within that, I might consider it. But the routines that they’ve given me so far would be at least three doses a day.
Steven (36 years old, HIV-positive 13 years): I can’t take a course of antibiotics for 7 days, let alone taking pills twice a day....I would just forget taking them....I haven’t worked for 12 months. I’d have to have, like, a daily routine to be able to handle it. At the moment I get up at 9, 10, 11, or whatever, there’s no set time. Because I know that you’ve got to reasonably have a set time to take your pill first thing in the morning, or an hour before breakfast, and in the evening, whereas at the moment I don’t have a daily routine. If I was working, it would be easier to handle.

*Threat to morale.* About one-third of the men argued that a positive mental attitude was extremely important in maintaining their physical health, and felt that the relentless nature of the drug regimens would threaten that positive outlook. Most of these men based their judgment on their observations of friends taking antiretroviral drugs; a few drew on their own experience with other types of medication.

Alan (26 years old, HIV-positive 13 years): If I start taking these pills every day, 3 or 4 times a day, it’s like every time I’m going to take them it’s like confirmation that you’re sick, it’s, like, reinforcing it, you’re sick, you’re sick, you’re sick. Whereas what I try and do is, like, stay positive.

Philip (29 years old, HIV-positive 11 years): I spent the early years of my youth...getting over a really really bad skin condition, and you know, that was going on for 12-14 years, so I know what it’s like to have to take tablets and use creams every day, and it’s extremely debilitating to the morale more than anything else. And that, as far as I’m concerned, is the one thing that’s really kept me going. I don’t want to affect that too much....I don’t think that constant reminder of it would be very helpful.
Absence of symptoms. Thus far, the reasons for not accessing antiretroviral therapy that have been presented have all dealt with unwanted effects that the drugs would bring. Some of the men who cited these reasons explicitly added that they were particularly disinclined to suffer these effects because their health was currently good, in that they did not feel ill (or, at least, did not have any serious symptoms of AIDS). These men saw taking antiretroviral drugs not merely as adding something noxious to their life, but as doing so for no good reason. The saying “If it ain’t broke, don’t fix it” was quoted by several men to explain their attitude.

Warren (37 years old, HIV-positive 14 years): I’ve got all these years behind me….Why fix something that’s not broken? Although it is broken, my immune system is broken, but I’m not violently ill or whatever.

Consistent with the men’s focus on the absence of symptoms as a reason for not accessing therapy, they also saw the advent of symptoms as a reason for commencing therapy. When asked what, if anything, would cause them to start therapy, most answered that becoming ill would probably lead them to do so. Some men were prepared to start treatment immediately they experienced any AIDS-related illness.

Kevin (26 years old, HIV-positive 6 years): If I got sick I would go on them in a flash because I don’t want to get sick, it scares me, I hate being sick.

Others emphasised that the illness would have to be serious and protracted before they would agree to start therapy.
Brad (39 years old, HIV-positive 5 years): I think it would depend what the illness was. If I got a little KS or something, I’m not likely to change my whole lifestyle for the sake of seeing one KS on my forearm, but then if I was covered in them, that would be a different story. I think if I had one, first time, attack of PCP, I wouldn’t take, I wouldn’t go on to a permanent, life-altering thing of taking antivirals. Whereas maybe if I had two PCPs shortly together, then I might think about it.

While a significant change in T-cell count and/or viral load was also cited by the men as something that would impel them to commence therapy, this factor seemed to play less of a role in their thinking: only about half as many mentioned it as mentioned the onset of symptoms.

*Actions the men were taking*

Although the men were not on antiretroviral therapy, they were taking other actions to try to monitor and maintain their health. All were seeing a doctor regularly. Almost all were having regular T-cell and viral load tests. A few were taking prophylactic drugs to prevent AIDS-related illnesses. Almost half were making use of complementary therapies, such as vitamins, herbs, and Reiki. Two-thirds stated that they were being careful to eat healthily, get sufficient sleep, and perform regular exercise. Several said they had cut down on alcohol, smoking, and use of recreational drugs.

The above actions seem intended to address physical health directly. But the men also sought to address their physical health indirectly, through maintaining their mental health. Three-quarters reported deliberately trying to maintain their morale by one means or another. One strategy for doing this involved trying to compensate for the stress that HIV/AIDS had brought by changing other aspects of their life. Thus, for example, several men said they had learned to just
“walk away” from difficult interpersonal or work situations. Others made sure that they gave themselves special treats to try to make up for what HIV/AIDS had brought.

A second strategy for retaining a positive outlook involved not letting HIV/AIDS “take over” their life.

Philip (29 years old, HIV-positive 11 years): Getting dramatic about it wasn’t going to get me anywhere….That’s the way I’ve always approached it, I think. Which is what’s kept me healthy, with no treatments or anything up until now. I think it’s probably more attitude than anything else….I think that’s the key to it. My life doesn’t revolve around it. I know so many people whose life revolves around HIV, and it doesn’t do them anything but harm, as far as I can see.

We have already seen one manifestation of the strategy of not letting HIV/AIDS dominate one’s life: the decision not to access therapy because the constant need to take medication would act as a debilitating reminder that one is ill. Another tactic, in the service of the same strategy, involved avoiding the HIV/AIDS support groups with which the men had come in touch, since these were perceived to be composed of people who had “given in” to the virus.

Brad (39 years old, HIV-positive 5 years): I’ve found that it can be very, very depressing sitting around those support network venues…Because you see the same faces, they’re sitting around comparing T-cells and viral load. And before, it was blood transfusions. And they’re a very unmotivated, unhappy crowd of people, and they really don’t want, they don’t seem to want, to just enjoy the moment. And so I think that attitude is self-perpetuating, that attitude en masse, you get new people joining those groups because
they feel isolated without them, and then they might not have that attitude before they
joined that group, they join that group and suddenly they’ve got that attitude.

Several men emphasised that one should avoid giving in to HIV by continuing to work at a
normal job.

Chris (37 years old, HIV-positive 15 years): [T]he worst thing they can do is give up
work, because you don’t have that ritual, you don’t have that kick up the arse, ‘OK, this
is life, this is what I have to do to exist in life.’ They just sit there and mope around the
house, with no-one to talk to or do anything with.

One man sought to limit the intrusion of HIV/AIDS into his life by limiting the extent to which
he tried to keep up with new information about treatments.

Philip (29 years old, HIV-positive 11 years): [I]t comes back again to what I think has
been keeping me healthy. I don’t concentrate a lot on knowing about HIV, and knowing
about all the new stuff that’s going around, because I don’t want my life to start revolving
around it. I think once I start to do that, whether it’s silly or not, I think it maybe gives
the virus power.

Another man stopped having his T-cell count and viral load measured in order to avoid negative
effects on his mental state.

Warren (37 years old, HIV-positive 14 years): [I]t just sent for a six, sent me for a six.
And I’ve had enough of that, that’s why I stopped having the T-cells done. I don’t know
how other people deal with it, but for me, it affects me mentally and emotionally. And it’s just, for me to get up every day, to get into my life, is sometimes enough of a battle, … but with these results, having to deal with that at the same time. Oh my God! Heavens! Let’s just get on with life.

**Resisting unreasonable pressure to access therapy**

Resisting what was seen as unreasonable pressure to access therapy, and pride at having the personal strength needed to do so, were important themes in the men’s narratives. The pressure had come from doctors, gay community organisations and networks, and, occasionally, from friends. Almost half the men reported having been subjected to such pressure from one or more of these sources at one time or another. When the men spoke about this, it was often with considerable emotion; the matter clearly aroused intense feelings.

About one-third of the men thought they had been put under unwarranted pressure from their doctor. A few had changed doctors as a result, while others had succeeded in “training” their doctor to respect their views. The disagreements with the doctor had not been personal in nature – all the men emphasised that they had good personal relations with, and felt they could speak freely to, him/her – but related solely to the issue of whether to commence therapy.

Murray (35 years old, HIV-positive 5 years): I’ve always had the same doctor. He’s gay and he does a lot of HIV, has a lot of HIV patients. And he’s a very good friend of mine. 18 months ago we had a, like, a screaming argument with each other, when he screamed at me that I was in denial. And I said no, I’m not in denial, it’s a decision I’ve made, and I take 80 vitamins a day…and I take a herbal mixture and I take selenium drops, and I
take, you know. And he, literally, his words were, “Well, you can shove those up your arse.”

Brad (39 years old, HIV-positive 5 years): The last time, [my doctor] had a student with him, and he tried for the second time, in front of the student, to embarrass me into taking [the drugs]. For the second time I called his bluff, you know.

The men attributed doctors’ overzealous promotion of antiretroviral therapy to the narrow way in which they had been trained. They suggested that doctors are taught to make decisions regarding diagnosis and treatment on the basis of abstract sets of rules – in this case, rules relating to the results of T-cell and viral load tests – and find it very difficult to consider any matters outside these guidelines.

Warren (37 years old, HIV-positive 14 years): Doctors expect you to listen to them, and I do, but will someone tell the doctors to listen to me?...And stop treating my fucking test results and treat me!

The men’s attitude to their doctors may be contrasted with their attitude to the companies that manufacture antiretroviral drugs. If the men continued to respect their doctors despite disagreeing with them, they took a very different view of these companies. Several men expressed great scepticism about the motives of the drug corporations. They suggested that the corporations’ pursuit of profits was overriding the need for proper evaluation of the drugs. As evidence, they adduced the “propaganda” about AZT monotherapy in earlier years and the “fudging” of results that had been found in research funded by the drug companies.
Chris (37 years old, HIV-positive 15 years): I think they’re pushing products out too early. Because they’re not, some of the side effects are so severe, no, hold on, that couldn’t have been missed, you know. But then, they’re also looking at the dollar, as always. Don’t they make enough already?...I think they are putting some products out that don’t do anything, on purpose, just to make a quick buck out of a desperate market. I believe there’s actually some quite poisonous products that have gone on to the market, that they’ve had to rip off. That’s why I would like to have, like, an inquest into why these products actually manage to get to the market.

Murray (35 years old, HIV-positive 5 years): I’m very suspicious of the chemical companies, especially from, if you read about the early AZT releases and research...where, like, complete, like, elements of results were hidden...because they were funded by the chemical companies and they didn’t want any bad results coming out of trials. So I’m very suspicious of chemical companies because they’re out to make money, they’re not out to save lives. I don’t think they’re out to save lives...I’m so suspicious of them that I would even believe that they would slowly keep releasing further drugs that would just continue people’s lives because the more pills the more people take for longer periods of time the more money they will make.

Several men noted bitterly that there was a dearth of support from the gay community – both from community organisations such as AIDS Councils and HIV support groups, and more informally, from other HIV-positive men – for the decision not to access therapy.

Jerry (38 years old, HIV-positive 5 years): In the HIV community, ...you don’t even have the pro- and the anti-antivirals anymore, you’ve got the pro- and the middle of the
road....[Y]ou’ve got the extreme “hit ‘em hard, hit ‘em fast” and the other people....And every time they open their mouth to give an opinion, you’ll get a “hit ‘em hard, hit ‘em fast” person try to jump down [their] throat.

Warren (37 years old, HIV-positive 14 years): [T]wo years ago I was told by one of the HIV support officers at the AIDS Council here specifically that the AIDS Council would not support me for not going on to any drugs, any antivirals, whatever....If you look at the AIDS Council now, all their group supports etc., everything is geared towards those who want to go on to the medications. There is nothing, and I mean it sincerely, there is nothing available in this city for anyone who doesn’t want to go on to...antivirals....I’m just very thankful for the opportunity of just being able to talk about why I’m not on the medications....I just wish there was more support within the general gay community, the medical profession, and the AIDS Councils in general as well, for those of us who ... don’t want to take the medications.

Of the men who were in a relationship (almost half the sample), all felt that their lover supported their right not to access antiretroviral therapy. There were indications that a relationship could be put under considerable strain if there was excessive pressure from their partner to change their decision.

Warren (37 years old, HIV-positive 14 years): I met a beautiful man late last year and, you know, over a period of about 3 months we were kind of seeing each other, you know, quite regularly. And I, in the end I had to walk away from him, because – he was also HIV-positive, and on all these retroviral medications – and the last two times I spent with
him were him arguing the point, “Warren, you’ve got to go on these medications, it’s silly not to.” “Joe, see you later, bye, I’m not interested.”

While a few men considered that they had good support from their friends for their decision, most indicated that they generally did not discuss the issue with friends and did not look for support from them. Where friends pushed too hard for a change in decision, they either learned to stop doing so or the friendship ended.

It was clear, in about one-third of the cases, that the men were very proud that they had been able to resist the pressure to access therapy and, by nevertheless surviving, confounded the dire predictions that had been made for them. Most of these men attributed their ability to resist pressure to inner strength, in the form of personality traits of independence and stubbornness. Several also credited another type of inner resource with giving them the confidence required: an ability to “listen to their body” and intuit its needs.

Jerry (38 years old, HIV-positive 5 years): [Taking antiretrovirals] just didn’t sit right with me. I kept on forgetting to take them and I had to really question myself over this. I was constantly forgetting to take them, even though I had the routine down pat pretty quickly. And...I had to delve into myself and think, well, why is it I am forgetting to take them? And it was almost a subconscious thing, my body telling me not to take them....I’d rely upon that [more] than anything that was written or proven.

If inner strength was considered to have played a major role in explaining the men’s resistance to pressure, it was also seen as having contributed directly to their survival.
Brian (47 years old, HIV-positive 15 years): I wonder what the psychological profile is of people like me. Whether we’re all hard-faced bitches...Not your sweet little people that die when they’re told to...The women-oriented film that I most associate with would be Steel Magnolias...[T]hey’re pretty little flowers, but tough as nails underneath.

**Discussion**

It is clear that the men in this sample were to some degree in conflict with the prescriptions of the biomedical model for the management of HIV/AIDS. The study’s findings help to clarify the nature of the men’s disagreement with that model.

First, the results help to specify the precise scope of the disagreement. Dissent from the biomedical model could conceivably take a number of forms. One possibility would involve abandoning the model entirely, in favour of a different model (pertaining to some form of complementary therapy, perhaps). Another would involve accepting some (or even most) aspects of the biomedical model, but distorting or misrepresenting others, in order to make them fit a contrary model. Yet a third possibility would also involve accepting some/most aspects of the biomedical model, but this time totally rejecting other aspects.

It is the last of these possibilities that seems to best describe the attitude of the great majority of the men. For they in fact appeared content to go along with what the biomedical model has to offer in all respects save one: the decision of if and when to commence antiretroviral therapy. On all other matters, the men were quite conformable to the model. They accepted that AIDS-related illness is caused by HIV, they met regularly with their doctor, they did not mind learning about the new antiretroviral drugs, they had regular T-cell and viral load tests, and they did not object to taking prophylactic drugs against the common AIDS-related infections. The decision of whether to access therapy was the only point on which they differed from the model.
On that matter, they rejected the official recommendations; that decision they reserved for themselves.

Our results also suggest that underlying the men’s dissent from the biomedical model was a different mode of thinking than that required by the model. The biomedical model for the treatment of HIV/AIDS focuses on the reduction in viral replication and improvement in immune functioning (indicated, respectively, by the results of viral load and T-cell tests), and the consequent amelioration of long-term health, that are statistically likely consequences of antiretroviral therapy. All other features of the situation are deemed to have the status merely of secondary phenomena; they are relegated to the background. Further, the model considers that the most reliable information is that which derives from trials conducted by scientists and is then transmitted to patients by those trained in medicine; information from other sources is considered less worthy of attention.

These characteristics of the biomedical model mean that it requires thinking that is abstract, in the sense that it is at quite some remove from the “here and now” of immediate experience. The emphasis is on entities that cannot be directly apprehended, but must be inferred through tests (viral loads and T-cell numbers); on features that will appear only in the distant future (long-term health versus illness); on information originating in sources remote from the self (the results of medical trials); and on assessments that deal with aggregates rather than the individual case (statistical probabilities). Aspects of the situation to be relegated to the background include those that would be much more salient in immediate experience, since they act in the short-term (the highly unpleasant effects that accompany antiretroviral therapy, the fact that one currently has no symptoms of AIDS-related illness) or exist close to hand (the experiences of one’s own social network regarding antiretroviral therapy).

In fact, much of what the men in this study had to say revealed a very strong focus precisely on those features that are devalued by the biomedical model. The men’s emphasis was
on the noxious accompaniments to antiretroviral therapy that they would have to endure in the short term: the side effects, inconvenience, and assault on their morale, that they would experience. They did not regard these as merely secondary phenomena; rather, they considered them to be as important as, or even more important than, any benefit they would eventually derive from therapy. They held tangible symptoms of AIDS-related illness to be all-important, seeing in the fact that they did not yet have serious symptoms an indicator that therapy was not yet appropriate and agreeing that if they developed symptoms treatment could commence. They tended to draw the evidence for their conclusions from individual cases near at hand – the experiences of their friends or, less often, themselves – rather than on the aggregated results provided by medical studies carried out by scientists. And they deplored the narrowness of the medical training that they believed teaches doctors to make decisions about treatment on the basis merely of rules regarding T-cell counts and viral loads.

The disinclination of these men to think abstractly in the way required by the biomedical model should not surprise us. Research in psychology has amply demonstrated that abstract thought is relatively rare (Gold, 1987; Johnson-Laird, 1983; Kahneman, Slovic, & Tversky, 1982; Pinker, 1997). Further, the medical anthropology literature relating to conditions other than HIV/AIDS reports reactions similar to those of the men in this study. Ito (1999), for example, found that Vietnamese refugees entering the United States were reluctant to take drugs to treat inactive tuberculosis because they had no symptoms of the disease and the drugs had unpleasant side effects. Her results also suggested an important role for information from one’s immediate social network, since having friends or family who had experienced side effects was associated with noncompliance to the treatment. Browner and Press (1996) reported that pregnant women in the United States tend to reject biomedical recommendations that would be too inconvenient in terms of the requirements of everyday life. Davis-Floyd and Davis (1996) found that midwives in the United States decry the biomedical tendency to manage pregnancy merely by applying abstract
rules relating to test results. All these findings clearly recall the comments made by the men in the present study. It is, of course, necessary to be cautious about generalising findings obtained from our convenience sample of just 20 men. The fact that our results find echoes in the literature on conditions other than HIV/AIDS helps increase one’s confidence in them.

The present findings are consistent with, but go considerably beyond, those obtained in Gold et al.’s (in press) quantitative study. In that study too, the great majority of respondents were found to have regular T-cell and viral load tests; and side effects, toxicity, inconvenience, threat to morale, and current absence of symptoms featured prominently as reasons for not accessing therapy. This convergence across studies using very different methodologies again increases one’s confidence in the findings. The present study added to that of Gold et al. (in press) by recording additional details on matters covered in the earlier study (further details about side effects, for example); and by investigating areas the earlier study had neglected (the actions taken to address one’s condition, for instance, and the experience of unreasonable pressure). Most importantly, allowing participants to cover a broader range of matters, and to do so in their own words, allowed patterns to emerge that had not been indicated by Gold et al.’s data. Particularly revealing was the emphatic nature of some of the comments made by the men; the depth of their feelings, which had gone unrecorded in the quantitative study, was very apparent in the qualitative one.

What are the practical implications of the findings? Perhaps the most important, in our view, is the need to treat the reasons gay men give for not wanting to access therapy as entirely worthy of respect and consideration. This may come hard to those whose training and investment is in the biomedical model. From the point of view of the model, it is tempting to discount the reasons given. Even the argument that the stress produced by a demanding drug regimen might negatively affect physical health – an argument that has, after all, a basis in medical evidence (Robinson, Mathews, & Witek-Janusek, 1999) – would be seen as furnishing entirely insufficient grounds for rejecting treatment that could be life-saving.
Nevertheless, it appears vital not to ride roughshod over the arguments of those who are reluctant to access therapy. The men in this study felt that they had had to struggle against unreasonable pressure to access therapy, were very bitter at having had to do so, and took considerable pride in having resisted the pressure. So central a theme was this for some of the men that their narratives seemed couched almost in mythic terms, coming across as the story of a “hero” constantly beset by “trials”. Their accounts suggested that resistance to pressure had become an important part of their personal identity. Simply dismissing or denigrating such men’s concerns is unlikely to be useful. It may cause them to resist the idea of accessing therapy even more strongly. Or, if it does lead them to access therapy, they may do so only grudgingly – something that is hardly conducive to good compliance with the treatment regimen. Our best advice is that doctors, treatments advisors, and formal and informal support networks should try to help patients clarify for themselves, calmly and clearly, the advantages and disadvantages of therapy. Having listed their reasons for not wishing to access therapy, patients should be encouraged to reflect on the adequacy of each, evaluating it carefully. Such an approach, which seeks to heighten, rather than to supplant, the patient’s own sense of agency and decision-making, seems likely to lead to more positive outcomes than would a more prescriptive approach.
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