

# HIV patients and their experience of HAART



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# Aims

- Situate use of health technologies in context of HIV management
- Outline a contextualised account of the patient experience
- Situate the contrast between patient perspectives and the emerging medical model

# Method

- Data from the in-depth interviews with HIV positive people (n=68) including gay men (n=21), heterosexual men (n=7), heterosexual women (n=5), a haemophiliac man, an injecting drug user and people of African descent living in the UK (19 women and 14 men)
- Sixteen relevant service providers (two charity directors, nine HIV clinicians, an HIV psychiatrist, an HIV liaison nurse, an HIV counsellor, an HIV outpatient nurse, and an HIV charity worker).
- Interpretative phenomenological analysis (IPA)

# Structure of talk

- **Medicalisation and the production of optimism, hope and certainty**
- **Invisible, yet measurable, health and embodied uncertainty**
- **The narrowing focus of clinical care**
- **The transformation of the patient**
- **HIV treatments and the paradox of health**
- **The reality of conflicting priorities**

## **Medicalisation and the production of optimism, hope and certainty**

- The rapid speed of technological development (CD4 tests, tests of viral load, resistance testing)
- The introduction of highly affective anti-retroviral therapy (HAART)
- Medical technologies transformed HIV diagnosis from terminal disease to chronic manageable infection

## **Medicalisation and the production of optimism, hope and certainty**

- Reduced death rates, reduced opportunistic infections
- Effectiveness of treatments demands their assimilation into people's everyday lives
- Clear process of medicalisation and technologisation

## **Medicalisation and the production of optimism, hope and certainty**

R: People were dying. The wards were full of people dying.  
(HIV Nurse)

Without doubt. I mean without doubt I mean I think yes you know in, in, in the history of this particular infection and I think how we manage it I mean there's no doubt. I mean I think you know we've gone through various stages from you know a medical approach to a holistic approach to a palliative approach. And I think yeah, I think we're pretty firmly back I think in the medical approach. No doubt. (HIV Clinician)

I suppose what we now have is a tool of optimism, of relative optimism, I think that we can now use which we didn't have before.  
(HIV clinician)

## **Medicalisation and the production of optimism, hope and certainty**

‘Imagine that your health is like a train running along a track, and when you reach the end of the track you become ill. Two things tell you how soon you will reach the end of the track. Your T-cell count tells you how much of the track you have left - the lower your T-Cell count, the closer you are to the end of the track. Your viral load tells you how fast the train is travelling-the higher your viral load, the sooner you’ll reach the end of the track.’ (Roche, Research, diagnostics, therapy and disease management, 2000)

<b>Viral load</b>	<b>Risk of AIDS in the next 3 years</b>
1,500-7,000	2%
7,000-20,000	8%
20,000-55,000	16%
Above 55,000	43%



## **Medicalisation and the production of optimism, hope and certainty**

- A sense of the bad old days and the good new days
- An emerging sense of certainty
- A clear sense of linear illness and health trajectories
- A sense of the manageability of HIV

# **Invisible, yet measurable, health and embodied uncertainty**

- The efficacy of treatments is measured in CD4 and viral load (blood tests)
- Subjective health (side effects) are negated
- Side-effects must be managed
- No longer a death sentence now a life sentence

## **Invisible, yet measurable, health and embodied uncertainty**

**Another thing is that people will be trying treatment, increasingly people try treatment when they're well, and when you do bad, it's a kind of act of faith that the treatment's going to keep you well, you know looking at your blood results and having some trust in your doctor when he says that if you don't take these you'll get sick, well then if you're feeling well when you're starting therapy, all it can do of course is make you feel sicker. Any benefits they have has to be your faith in your clinical care and in the medication and in what you believe in terms of medication, so again, if you're feeling well and then you start getting ill, and the only illness you have is related to the combination therapy, well then you know it's very difficult to have much faith in the therapy. So, again, a problem (HIV clinician, London)**

# **Invisible, yet measurable, health and embodied uncertainty**

You can't actually feel any immediate results, when you take the drugs you know. They're kind of like silent bombs, I suppose that go off inside you, and you know it's not really reported to your own senses, you know. So you rely on the doctors in fact, to tell you that these things are working, or have an effect (HIV positive heterosexual man, Glasgow)

# The narrowing focus of clinical care

**You know, people had short lifespans, so people did a lot of things and were very active and it didn't feel like people were just dying, slowly dying, it was much more than that. Those half hours are filled up with all that stuff, it hasn't gone away, a lot of those issues are still just as relevant now, but there's no time to deal with them, and of course we're seeing far more people. Well, great, people aren't dying, people are still being diagnosed with HIV, people are still getting HIV, and again something needs to be... something's squeezed there, I think patients are noticing it and we're noticing it as well that it is not possible for us to be all things to all people, we are going to have to compromise and move things, and some of that stuff is the wider look at people's lives. When we do look at people's lives we're looking at their lives in quite a focussed way, like, yes we are concerned about your chaotic lifestyle, but only insomuch as it interferes with your ability to take combinational therapy, rather than it being something in itself. Again, maybe that's right. People have friends and families and communities where they can lean to, where they can get support, I mean why should they come to a doctor to get that kind of support, you know? Not that we don't care (HIV clinician)**

# The narrowing focus of clinical care

**Whereas now you know he's become quite a specialist technician and you know feeding people HIV drugs. He doesn't touch anybody he doesn't I mean he's never touched me .... You know its, there's a huge distance... at times you can literally be in and out the door in a matter of minutes, and sometimes you think you do actually have quite a serious life threatening illness em that could potentially have a huge amount of problems, not just the virus but you know other problems, but like I said I don't actually remember the last time anybody actually touched me, not that I'm expecting them to, but you know they used to always check your eyes, they used to palpate your stomach they used to have a general look round you. They don't do that anymore. (HIV positive heterosexual woman)**

# HIV treatments and the paradox of health

**I took them to make me better and they were actually making me ill (HIV positive, African heterosexual woman)**

**Whilst at the same time trying to maintain people you know on antiretrovirals. So yeah, I mean on the one hand yes it's about going well, you know these, these drugs are there and these drugs are good. And you know they can get your viral load undetectable and get your CD4 count up and prolong your life and keep you healthy. But at the same time we don't want to specifically kind of scare people off taking them because you know they're gonna turn you into some strange looking character, and you know they're gonna make you suicidal (HIV clinician)**

# HIV treatments and the paradox of health

It was annoying because it's like you're given one thing, to keep you alive, but the thing that's keeping you alive is killing you bit by bit, you know, and then you've got to take, like now, (HIV positive, gay man, Glasgow)



# HIV treatments and the paradox of health

I've seen people get better. I've seen people get better. I mean the pros are more than the cons I think. Speaking from a woman's point of view, I've seen what they've done to some of my friends. You know the way a woman move, a woman is proud of the way she looks, you know a small waist, nice bum, nice legs and suddenly that's all taken away from you. And in a case where you haven't disclosed your status and people start seeing the body changing – that alone is enough to disclose your status. The practical issues around taking medication, how many times a day, you know, the restrictions, are for someone who hasn't disclosed their status who is in a relationship, when do you take your medication? Do you wait for a partner to go to your bathroom? What happens if you go away for a weekend? What happens if you're working for instance and you have to take your medication at lunchtime and your colleagues are there? (HIV positive African woman, London)

# The transformation of the patient

Some people must think "oh, I've gone through years of treatment just to come back to be recognised as an HIV/AIDS patient again, you know, and I think that's really hard and you can compare it to chronic illnesses, like diabetes, but they don't have, they don't have the stigma, they've got to take medications every day and there are a lot of similarities, but there isn't the stigma - and, you know, people tend to be older, not always, but tend to be older and in a lot of ways it's good but it is a bitter pill, you know, if that's not...(HIV positive, gay man, Glasgow)

# The transformation of the patient

I suppose there's a real danger with HIV 'cos of the complexities of combination therapy and the number of pills et cetera, that you end up dealing with somebody as like a receptacle for pills. You don't deal with them as a person and you're issue is going to become adherence. (HIV clinician)

# The transformation of the patient

People don't understand the full implications of what it is to live on drugs. I mean it's a relationship, it's a marriage, you know. People don't realise that there's no cure yet you know. Yes, the treatments are there but they don't work for everybody. You're just negotiating around it every day of your life (HIV positive, African heterosexual woman)

# The reality of conflicting priorities

**It's bad enough being HIV positive, they've got all the other issues to carry on with, um, relationship break down, unemployment, poor housing, um, and for a lot of them treatment is kinda number seven on the list of coping, this particularly applies to people from our asylum seeker population where, you know, but their concerns are um, survival one day to the next, coping on, used to be coping on vouchers, small amounts of cash, are they gonna get moved on, racial abuse and that, you know, number seven on that list is taking your pills, and I think that's a reality, although that's the focus of our consultations pretty much now, um, the for many people there's a whole pile of other things that are much more important to them that taking their pills, ultimately of course long term if you put treatments low on you list of priorities and you're on therapy it'll fail and you'll be in much more serious trouble, I can understand why that happens. (HIV clinician, Glasgow)**

# Health technologies in HIV

- **Policy, experience, research all reflect the impact of health technologies**
- **All these technologies present relatively straightforward simple technological solutions to manage the epidemic**
- **All face the challenge of marrying the psychosocial and sociocultural to be effective despite the rhetoric of medical progression**

# Health technologies in HIV

- HIV treatments require faith in a medical model in which health is no longer somatic but delivered through monitoring test results in the space of clinical interactions
- Clinical markers take precedence over lived experience or subjective well being
- Clinical interactions are increasingly focused upon diagnostic tests measuring health
- Critical issues such as adherence rely upon the assimilation of medical models into everyday life

# Treatments and tests as health technologies

- Medicalisation of HIV narrows the focus of what constitutes HIV management (for service providers, for people living with HIV, for clinicians, for researchers)
- However, there is a danger that technologies are prioritised over the psychosocial and it is ultimately the psychosocial that defines people's response to the biomedical