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## **Constructing Meaning in an Epidemic Interpretations of a Diagnosis of HIV Infection and AIDS\***

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AIDS is a disaster of global proportions. The World Health Organisation recently estimated there to be eight million people in the world who are infected with HIV, the viral agent identified by bio-medicine to be the singular and necessary factor in the development of the fatal illness called AIDS (NAB 1990). There are two epicentres of the pandemic. Called Pattern Two epidemics, African countries demonstrate predominantly heterosexual transmission of the virus and a short mortality shaped largely by a health ecology of low nutrition and lack of clean water, inadequate medical services and little or no public education programs. Pattern One countries are characteristically wealthy, industrialized nations with expression of the disease and virus transmission predominantly through homosexual sex and, to a lesser extent, intravenous drug use and heterosexual sex.

Australia clearly follows this Pattern One epidemiology. Cases of AIDS are predominantly recorded as occurring through homosexual transmission (National Centre in HIV Epidemiology and Clinical Research 1991), though rates of new infections through homosexual sex have been shown to have

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declined to near zero since the implementation of education programs by and for gay men (Connell et.al. 1988). Sociological research on a sample of gay men in Sydney and its regions, conducted in 1986/87, found the rate of infection at around 20% (Connell et.al. 1988), while another clinical study of a cohort of homosexual men in Sydney found a rate as high as 40% (Tindall 1986). Conservative estimates by epidemiologists put the number of individuals in Australia infected with HIV at over 13,000, over 75% of which were identified as being infected through homosexual sex. In terms of people with the later stages of the infection, AIDS itself, approximately 90% of all recorded cases in Australia, alive and dead, have been through homosexual transmission. Over 60% of all cases have been in New South Wales, and most of those in Sydney. At time of writing over 1,400 individuals in Australia had died of the disease (National Centre in HIV Epidemiology and Clinical Research 1991).

Sydney is the epicentre of the AIDS epidemic in Australia. It is here that the disease was first detected in a gay man. The first death from AIDS was recorded in Sydney in 1983. It was in Sydney that the earliest frontline organisations were established by gay men to provide financial assistance to the ill, and run education programs for gay men. It is these organisations which have become most significant - politically, culturally and in terms of provision of education and care services. Historically then, the largest and longest running collective response to AIDS in Sydney has been an innovative one from the gay community. This response was made possible by the early establishment of cooperative political relationships with both state and federal governments. Government recognition of a legitimate 'gay community' in Australia, and thus acknowledgement of government responsibility to its gay citizens, was a prerequisite for the funding which was to make possible the many professionally run care, support and education programs.

In this paper I approach allopathic medicine, or bio-medicine, as a hegemonic 'technology of the body' (Foucault 1977) comprised of symbols and meanings and related practices which construct the body as a passive container of disease agents. I discuss how people diagnosed with HIV infection and AIDS themselves have become positioned within this scientific discursive practice of the body. My examples discuss a range of life circumstances, from the individual and phenomenological, to the collective and political. I limit my consideration to the responses of gay men with strong 'attachment' (Kippax et.al. 1990) to Sydney's inner city gay community. The analysis is necessarily informed by this specific social and cultural context.

Finally, I consider the role of community based AIDS organisations in providing a structured intervention into the cultural organisation of meaning in the epidemic. While the discursive practices of these organisations are increasingly accepting of the ideologies of bio-medicine, they yet provide a counter-practice which challenges the adequacy of bio-medical research to respond to the urgency of the epidemic.

Data is derived in part from interviews conducted by the author and other researchers for the Wollongong AIDS Research Project in 1988/89, and from participant observation in Sydney's gay community based AIDS organisations from 1988 to time of writing.

## **Diagnosis - the creation of patient subjects**

*What does it mean to be diagnosed with HIV infection or AIDS?*

The clinical interpretation one receives at point of diagnosis is one which focuses on the body as an independent biological entity. A single etiological agent, a virus, is present in the body which works inevitably to inactivate the body's immune system. After early debate, within both medical discourse (Duesberg 1989, Evans 1989) and among affected communities (Lauritson 1987), this principle is now established as the dominant model in the medical conceptualisation of AIDS (Treichler 1987), one which is now rarely challenged. This is despite the lack of scientific understanding of the virus's role in the development of the disease.

This foundational truth of AIDS science, the HIV, is however overlaid with a constantly shifting and contested field of interpretations and truth assertions. For example, the range of diseases by which full AIDS is diagnosed is under a continual process of expansion and refinement (Whyte & Cooper 1988). Theory of the natural history of HIV infection is being elaborated through empirically driven observations over time, yet it is still not known what triggers the virus from an inactive to an active state which ushers in immune deterioration. The therapeutic consequence of this causal uncertainty is controversy about when and how to best intervene in the course of infection (Friedland 1990).

As clinical uncertainty continues, the solidity of the biological model weakens and questions regarding the 'psycho-social' aspects of disease progression and management are gaining wider legitimacy. A broadening of the AIDS research agenda is symptomatic of a historical shift in medical practice from 'magic bullet' medicine against infectious and bacterial disease (Brandt 1987) to a focus on the problems of management of long term chronic illness (Willis 1983).

The intervention medical science provides for HIV infection at this time is limited to the application of specific action pharmaceuticals to an identified etiological agent, HIV, or its expressions. What is absent in this technology, when contrasted with the healing techniques of non-industrial cultures, is the contextualisation of the unwell individual within his/her wider social universe. Bio-medical intervention atomises the individual from the social and cultural context, and removes the subject from the body. The biologically defined human body, not the social subject, is thus constructed as the object of the medical gaze and its interventionist practices. All that is required of the passive 'patient' is consent. However, even this minimal role in healing is increasingly under threat with, for example, the introduction in some Australian states of compulsory HIV testing of hospital patients (Garcia in press).

To the newly diagnosed patient subject, knowledge of being HIV infected presents a hermeneutic crisis. The meaning of this new clinical status is highly contested - amongst doctors, scientists, community health workers, political activists and infected people themselves. To be classified as 'HIV infected' is to not only be given a stigmatising label of deviancy, a 'spoiled identity' (Goffman 1963), as to be presented with a new field of contested signifiers from which to reconstruct life meaning. Living with HIV infection or AIDS is less about scientific progress and more about interpreting contested knowledges and making therapeutic and other significant decisions based on such interpretations.

How long do I have to live? What can I do to preserve my life? What can medicine do to keep me alive? What can't it do? These are common questions asked by newly diagnosed individuals. They are questions to which medicine cannot give satisfactory answers.

From the moment of first diagnosis, the emerging subject's ontological existence is framed in terms of a continual negotiation between the pull into a medically defined existence, and attempts to resist that pull. As illness progresses, the patient subject's social identity is increasingly linked with the fact of viral infection. The end result of this sequence is the surrendering of the self to the life-sustaining technologies of bio-medicine. The very meaning of life is increasingly defined in bio-medical terms.

Creativity of interpretation is supplanted by surrender to technology.

## **Diagnosis and uncertainty**

The detection of HIV in a human body serves the needs of medical science to identify etiological agents of illness, yet for the individual who

embodies that condition, this clinical diagnosis is unstable in its meaning. Listen to this gay man's consideration, for example:

. . . to feel comfortable I have to find out about what it really means, like maybe you never progress, 20 years, you never progress, who knows? because I've had one school of thought saying . . . you're in a higher risk group of progression and I've had other people actually say the opposite, medical people say some things happen with people who are HIV and Hep(atitis positive) but the HIV doesn't seem to be progressing, at least not so fast, so you listen to one, you listen to another, you just have to come to terms with it yourself . . . I've got to expect that I'm able to get on with things without it hanging over me like it used to (WARP interview, 008).

We see here the hint of a range of available interpretations, sometimes in conflict with each other, which the individual has available to select from and build personal meaning. The construction of meaning proceeds through a dialectical exchange between available discourses and a continual reading of one's own body.

. . . the most difficult thing still is . . . the uncertainty as to just what the future holds . . . I carry around with me all the time (thoughts such as) OK, I've had the virus for 5 years now and I'm perfectly well, but what's it going to be like in 2 years time, 4 years time, 5 years time, 10 years time and so on . . . there's a fear of loss of some sort there (WARP interview, 040 3rd)

. . . the most difficult thing is seeing a number of friends who are antibody positive getting sick and . . . is this going to happen to me and I don't want to have to go through this process . . . looking at people going through that all the time and wondering am I next (WARP interview, 1001 2nd)

For these men, uncertainty regarding prognosis is identified as the prevailing difficulty they face. This uncertainty is born of the inability of biomedicine to provide information to them about the meaning of their diagnosis beyond the simple fact of their infection status and the inevitability of illness and death at some point in the undefinable future. The search for meaning and order in a new terrain of uncertainty thus becomes an accentuated ontological pursuit.

The first major theme which emerges from this pursuit of meaning within the context of life uncertainty is an invigorated sense of *care of the self*.

I tend to be fairly positive about things . . . I know I don't look after myself as well as I could but even so I don't do things that are really clearly very harmful to my body . . . so I look after myself in that way (WARP interview, 040 3rd)

. . . we are all going to die, but we have to look after ourselves, not because you are dying but because there are 2 roles - one we are dying, which is the wrong one, I know that we are dying, but we have to make the most of it . . . I'm a person who never has drugs, I don't drink alcohol, I have a good time (WARP interview, 026)

A professional gay man in his mid thirties, shortly after an unexpected diagnosis of full AIDS, explains to me:

I don't know how to be any more careful, I don't smoke and drink, I don't stay out, I eat well, what more can I do? (Author's fieldnotes, 11/11/90)

Again:

In the beginning every time I got a cold it was like this great big drama, now I don't get a cold any more, I don't stand in the rain, I don't stay out all night, I don't take too many drugs, I don't go out dancing all night, I don't drink too much or I drink less (WARP interview, csn 80 2nd)

Here we see the knowledge of HIV status to have implication for the manner in which one conducts ones life. Medicine itself will not formally prescribe this kind of behavioural regimen. This is partly because the rationalistic discourses upon which doctors base their practice will not recognise, at an empirical level, any predictable correlation between 'lifestyle' factors and time to progression. Hence, even while some doctors acknowledge in private the possibility of lifestyle factors in disease etiology, their commitment to rationalism excludes them from framing advice on this issue in any systematic manner. Advice of this kind must be sought outside the medical consultation context, and can be found in a number of forms, from within personal networks or other informal sources, to more systematic discourses associated with alternative, 'holistic' health beliefs. Throughout the course of the AIDS epidemic many people with HIV have in fact pursued, sometimes very systematically, sometimes illegally, unapproved and uncertain treatments in the hope of a cure medical science has to date been unable to provide (Abrams 1990).

Many of those encountered during research were found to have developed some regimen of action on the self as a result of receiving a diagnosis of HIV infection. Other research among gay men have also mapped such responses to the presence of the epidemic (Spencer 1983). One response is the, at times aggressive, pursuit of 'health and fitness', a regimen culturally supported by a wider ethos among emergent urban middle classes, of caring for the self and presenting an aesthetically pleasing self to others. Another form of response to be discussed, and one not exclusive to the former, is to politicize one's status, to become an AIDS activist, and to join the lobby for social reform.

## **Encounters and negotiations with bio-medicine**

It is virtually impossible, and given the lack of care alternatives, undesirable, for individuals at later stages of infection and illness to be completely independent of medical intervention.

Accompanying an intensifying relationship with doctors, clinicians and researchers, is a desire to translate medical information into practical knowledge. Some evidence is available in the medical sociology literature that unequal relations of power are sustained in the doctor/patient

relationship through the manipulation of jargon and technical languages (Waitzkin 1979; Armstrong 1982, 1984). Our research among gay men suggests degrees of awareness of this relation of power and a desire to correct the imbalance.

One response, available to those with relatively high levels of education and language skills, is to attempt to meet doctors on their own linguistic terms. The following gay man explains his determination to negotiate understanding of medical scientific knowledge.

I'm determined to do it. I sit there with an encyclopedia and a medical dictionary and just work my way through it . . . I might skim through some of it one week and then another attempt to read it again, its like I remember when I was at school when you're young you learnt things slowly, and you learnt paragraph by paragraph . . . it takes a long time to sink in . . . interpreting some of their information or their graphs something like that, it feels good to be able to look at it and finally understand what it means (WARP interview, AC 2nd)

A gay man I will call David speaks about his decision, in consultation with his General Practitioner, to modify his medication dose after experiencing negative side effects.

they [hospital researchers] weren't very happy with it . . . but I'm well educated, I can speak to them in their own language, I'm not easily intimidated, you need to inform yourself as much as possible because they wont tell you (Author's fieldnotes, 28/8/90)

We see here the imperative, in the pursuit of knowledge of self, to gain entry into and mastery of the dominant discourse of medicine. The subject has been defined as a 'patient' through diagnosis, and that new subjectivity is thereafter continually refined and elaborated through a learning of the system of knowledge, with all its symbols, grammars and lexicons. We seethere by the expansion of medical ideologies through the capturing and construction of new 'patient' client subjects. The subjects themselves must internalise the paradigms of bio-medicine if science is to succeed in manipulating the patient subject. In this sense, we can begin to see a hint of the self-fulfilling philosophy of medicine. Belief in its precepts advances those precepts further by promoting compliance.

Doctor-patient relations have a potential to be transformed, however, when patients, the less powerful partner in the equation, are more fully able to communicate with their doctor through a greater common knowledge of the medical issues. The sharing of the symbolic system of bio-medical language, its technical jargon, labels of therapies, and associated ideologies of treatment, may equalise the power relationship allowing, potentially, the patient subject more determination in treatment.

David provides the following observation on his relationship with staff at a Sydney hospital after a short period of hospitalisation with a common opportunistic infection:

I expect lots more information, I have no problems getting answers . . . they tend to theorize a lot and make unsupportive answers, . . . but the staff are good and the doctors are approachable, I would be left in the dark if I didn't ask questions. As far as I'm concerned the treatment I've got has been first class, because I'm informed and people know I'm informed they're a little more careful to give me answers, I'm treated as a quasi professional (Author's fieldnotes, 3/9/90)

In accord with the liberal educationist principles that knowledge is the basis of self-empowerment, the above vignettes suggest a belief that technical information and education is a key to empowerment in the doctor-patient relationship. But to what extent is this empowerment one which translates into individuals having some real determination over the healing process?

In following David through a period of increasing illness, it becomes evident that his negotiating power becomes reduced the more ill he becomes. We see a growing dependency on medicine, both in physical care terms, and in terms of his belief in its ability to provide efficacious treatment.

In a conversation two months after the previous one, he explains:

I'm feeling really awful, the treatment has really fucked me over . . . I feel worse than I did when I was doing (treatment) . . . I'm feeling more depressed than I ever have in my life, like nothing about my life seems worthwhile and nothing I try to do seems worthwhile . . . after all I've said about taking control there's still something about being in that situation that makes it very hard to make your own decisions, you wonder whether you have all the information, whether you're able to make decisions (Author's fieldnotes, 13/11/90)

The combined effect of the intensifying bodily experience of illness, together with the intensifying management of the body in a hospital setting, works to more completely alienate the individual from the healing process. This alienation later led David to intense feelings of hopelessness and considerations of suicide, thoughts associated, significantly, with medical treatment manipulation.

I came home and went to bed and laid there for 2 hours and fantasized about how I was going to end it all. I'm just really fed up with it all . . . I thought of putting myself into hospital and stopping all my treatments. (Author's fieldnotes, 10/1/91)

We see here, then, the totality of illness in this individual's life. And the meaning of that illness has become framed in wholly medical terms. The near total medicalisation of his illness leads to the point where even death can only be conceptualised within the context of the medical apparatus. Life and death have become meaningful in bio-medical terms only.



As one's interaction with medicine intensifies, a contradiction develops. The dialectic interplay between technological intervention and the subject's ongoing reading of the body place the individual in the predicament of simultaneously being dependant on, and suspicious and resistant to medical intervention.

Paul has been diagnosed with AIDS for over two years. He has attempted AZT treatment three times and on each occasion volunteered to cease treatment because of the effects which he found intolerable.

I've just gone off AZT again yesterday, for the thirdtime, I was only on it again for 1 week but I felt so awful, I could hardly walk, couldn't speak, I was just a zombie, so I missed my dose yesterday afternoon and again last night and today I feel terrific. (Author's fieldnotes, 15/1/91)

The failure of medicine to provide Paul with a treatment that is satisfactory to him and to the expectations of medicine itself, together with his ongoing experience with doctors, has allowed him to develop a scepticism of medicine's competence to both describe reality and have a beneficial effect on his life. Here he discusses how science manipulates statistics in a way which he thinks does not accord with the reality he experiences.

If you look at the statistics . . . actually only about 30% [of infected people] or something are very sick or dead, when the statistics said many more should be, so you just can't trust statistics, you know what they can do with statistics! So if you look at what's happening in the world it's nothing like what the statistics say. You begin to suspect what their motivations are forgiving the information they do (Author's fieldnotes, 15/1/91)

This sceptical anti-positivism has been further reinforced by the inaccuracy of a prognosis given to him recently. His decision to reject the prognosis lead him to further challenge science and reposition himself as an educator to his doctor.

I said to my doctor six months ago 'what's my chances', and he said, 'well, I'd say you've got six to eight months', and I was absolutely devastated, and that's based on statistics. I asked for statistics, but I was sort of expecting, you know, nice statistics. So I decided to beat [defeat] it. When you get a prognosis like that you can't just accept it. You have to fight it. People said to me 'get another doctor'. But you can't really, you're talking about one of the leading specialists in the field. You don't have any choice. The only thing you can do is educate them [doctors] (Author's fieldnotes, 15/1/91)

Clearly, Paul sees himself in a relationship of dependence with medicine, yet it is not an inflexible one. He sees himself as holding an alternative view of the world to that of science based on his experience of illness and observations of others. This alternative view he thinks contradicts those observations made by science. These experiences are strong enough to not be substantially threatened by the dominant medical paradigm. Rather than

rejecting science, therefore, he sees his relation to it as necessary and inescapable. In this circumstance the only option is to try to modify the relationship to better accommodate his needs. In the last analysis, he sees himself as having a personal role in the progress of science.

## **The signification of drug therapy**

In 1987 the US Federal Drug Administration announced the licensing of an anti viral drug Azidothymidine (AZT) for people diagnosed with full AIDS (Hirsch 1988). Initial experience with the drug suggested it would be more efficacious and less toxic for use in those with less severe conditions (Fischl 1987). Due to demands from community AIDS organisations and activist groups in Australia, access was granted to those in earlier stages of HIV infection before clinical trials had generated the traditionally required amount of information on the use of the drug for this purpose (*Sydney Star Observer* 24/8/90). While winning early access to the drug was acclaimed by activist groups as a victory over indifferent bureaucratic machinery (Whittaker in press), the scientific uncertainties of the effects of the drug in early use remained (Friedland 1990; Reudy 1990).

What are some of the existential dilemmas this widening access presents to people who are now eligible for treatment such as prophylactic AZT?

Les made the decision to begin early treatment, via a clinical trial, out of belief in science and a desire to reap the perceived benefits of medical monitoring.

If there was going to be some beneficial effect then so much the better, its better to be in there if it did turn out to be useful, (also) its going to help prove if it does work. I do have faith in the scientific system (Author's fieldnotes, 26/8/90)

We can appreciate then, that the incorporation of bio-medical paradigms in the world view of potential research participants is an absolute prerequisite if medical science is to continue to pursue its research agenda. Similarly, belief in the paradigm of science is a requisite for the expectation of positive effects in the scientific healing method. Science disguises this symbolic aspect of medicine, however, by inculcating distrust in psychological processes in health. For example the 'placebo' effect is constructed in science as an effect to be eliminated, not as a positive effect of healing ritual. Distrust of anything other than the predictable effects of pharmaceutical agents is the desired world view.

The decision to participate in scientific research trials, whether it be from a desire to aid its progress, or gain access to regular health monitoring, or to access information, presents an existential dilemma to the trial participant.

Being basically healthy you find yourself caught in the medical world, but that's unavoidable, there's still something funny about being healthy and popping pills every day, I don't feel like getting involved in the medical establishment any more than I have to (Author's fieldnotes, 26/8/90)

In time the result is one we have become familiar with amongst these men:

There's the problem about who to go to about what to do. You end up being your own expert. While we are saying we should be consulted, on the other hand we don't have a medical background. You're suddenly faced with the situation of having to be expert about something that no one's expert about, also there's the problem about deciding how much poison to put into your body. (Author's fieldnotes, 26/8/90)

With an extremely limited range of bio-medical therapies available for HIV infection, the medical research apparatus has come under increasing scrutiny and political lobbying to speed up its method of developing drugs. Scientific performance to date has not matched learnt expectations, almost as if the layperson believes in the potential of science more than its own practitioners.

The trust in science has been reinforced by a more recent deflection of criticism from medical research to the state as a target of political action. As the epidemic progresses in this country, but more widely throughout the industrial world, the state has come under increasing criticism for its inflexible bureaucratic mechanisms for approving and releasing drugs for use by people with HIV infection. Largely inspired by styles of political lobbying developing in the States, the last 2 years have seen a stepped up campaign by various community based AIDS organisations in Australia to release AZT and other anti-virals for earlier use, even before the research apparatus has completed its scheduled trialing.

For example, at the recent National Conference on AIDS in Canberra, both the opening and closing plenaries were framed by the demand by HIV positive activists for the state to expedite the development of and access to HIV treatments.

We demand . . . effective research programs and trials with realistic protocols which are designed to provide access to drugs for people who need them, to save their lives (ACT UP 1990)

I look for your support in standing to call on the minister and ADEC (Australian Drug Evaluation Committee) to approve with all expediency the wider and earlier use of AZT therapy for people in this county. It is an option which we demand (Jarman 1990)

This campaign resulted in a sizable report being compiled by a federal investigative committee which recommended streamlining drug development and access in this country.

The development of antiviral technology into preventive medicine signals the extension of medical intervention to those not only ill, but to those potentially ill as well. The willingness on the part of community groups to accept the argument for early intervention is predicated on the preliminary results of trials of the anti-viral AZT conducted in the US, together with the assumption that more effective bio-medical treatments will become available in the near future.

## **Conclusion**

Despite the recognised failings of medical science to yet produce any effective sustaining therapies for HIV infection, gay men continue to hold a faith in science far beyond what many of its own practitioners support. Indeed, this faith is strengthening over time. Deep rooted cultural beliefs in the progress of the rational mastery of life, fuels, I would argue, an uncritical faith in the ability of medical science to develop a 'magic bullet' for HIV infection. This faith is in fact contrary to the broader shift in bio-medicine away from technological quick fixes and toward a technology of long term management of illness. The organised gay community response is one which takes many premises of medical science for granted. Demands are phrased in terms of streamlining the progress of medical science, not in terms of questioning the basic principles of its existence, and demonstrates an ignorance of the historical reality of bio-medicine's limited achievements.

Our response to medical science should extend beyond simply pressuring for a faster, perhaps illusionary progress. By limiting ourselves to this form of critique we risk submitting ourselves more profoundly to the hegemonic structures which deprive us of a broader scope of action. Our critique must extend to the possibility of rejecting altogether the supposed superiority of science in its ability to define for us a better life. Rationality and positivist ideologies are not intrinsically superior world views and are themselves determined by social interests such as career advancement, profit, and the intellectual construction of paradigms.

My fear is that the growing influence of bio-medicine in all aspects of social life, an expansion starkly demonstrated by the AIDS epidemic, can only lead ultimately to the impoverishment of both our ability to pursue the good life, and experience dignity at death. That is, unless both medical science and the popular uncritical acceptance of its agendas are challenged.

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