

Adherence and communication: Reports from a study of HIV general practice

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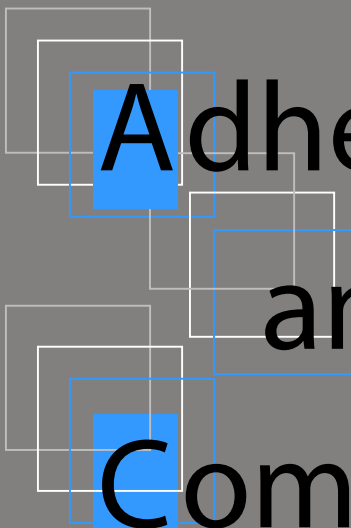
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Adherence and Communication

Reports from a study of HIV general practice

Kane Race
David McInnes
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Michael Kidd

ADHERENCE and COMMUNICATION:

Reports from a study of HIV general practice

Pills in Practice:

Approaching the patient's world in HIV general practice

Compliance Supportive Communication:

Understanding interactive sequence and knowledge/power relations in HIV treatment

Kane Race
David McInnes
Elisabeth Wakeford
Veronica Kleinert
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Monograph 8/2001

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FOREWORD

Since 1995 the expression of HIV disease in Australia has changed considerably in the direction of chronic illness. The presence of effective but highly toxic treatments for HIV - with low tolerability, and requiring a high level of adherence - creates a difficult problematic for general practitioners who prescribe them. Not the least of these difficulties is how to begin to identify what is going on for the patient in order to engage with it for the purposes of enhancing adherence, and - more generally - health and wellbeing. These reports examine some of the ways in which practitioners are addressing this problematic, both by their own account (as described in *Pills in Practice*), and in terms of actual instances of exchange with patients (as shown in *Compliance Supportive Communication*).

HIV general practice is unusual in the sense that its practitioners often share - or have some understanding of - the socially produced experience of stigma and shame that attends many of the practices relating to the conditions that are seen in practice. This creates unique forms of clinical practice, from which there is much to learn. We have used this opportunity to describe and evaluate some of the forms of practice and communication that have emerged in Sydney in this context. Through discussion and reflection, the various strengths of these different techniques might be drawn upon to promote better practice.

Pills in Practice

Approaching the patient's world in HIV general practice

Kane Race, David McInnes, Elisabeth Wakeford, Michael Kidd, Marilyn McMurchie

INTRODUCTION

I think that individuals just change over time. An individual from one point to another point over two years can be a different person. Plus the fact is that over two years time issues often come up and they change the role that the drug might have, the perspective they have on it...

- Blair, gay male high-caseload GP

This report focuses on accounts of HIV General practice as it pertains to adherence with HAART. The problematic that this research shares with doctors (and others) is how to assist patients to be sufficiently 'committed' to therapy to produce good health outcomes. It approaches this question by looking at how doctors account for their exchanges with patients (in this report), and at actual interactions with patients (in the second report). The premise here is that these exchanges have some influence on a patient's capacity to adhere.

The presence of effective but highly toxic treatments for HIV, which have a low tolerability but require an unusually high level of adherence, creates unique problems for those who prescribe and are prescribed them. It has generated responses that are as various as there are HIV practitioners. The problem might be framed as one of how to engage the patient's world in the presence of this demanding pharmaceutical technology. Different considerations — ranging from how to treat patients' priorities, beliefs, and ways of living; to how to ensure the optimal suppression of HIV replication; to how to cultivate a sense of self-esteem and empowerment — come into play, and can sometimes appear incompatible. These occur in the context of applying a complex and rapidly changing body of science within which there is often some divergence of opinion and many competing interests,

including the interests of pharmaceutical corporations, government agencies, individual patients, and organisations that advocate for PLWHA. Finally, they occur within a public health system structure that creates further constraints and pressures, including time constraints and other economic pressures that shape the form taken and services offered by practices, as well as the requests made of the clientele (such as requests to participate in clinical trials). This structure also offers some important benefits, including relatively affordable access to HAART and most other HIV medications, and the (declining) possibility of bulk-billing in some practices for general care (though, as is discussed within, the expression that HIV problems take in the context of HAART often exceeds 'general' care).

If HIV diagnosis created the possibility of being diagnosed as sick while feeling healthy, viral load testing has created the possibility of being diagnosed as acceptably healthy while feeling very unwell. This creates difficult positions for both doctor and patient. Often, doctors are put in the position of advocating continued therapy – and adherence to abstract and seemingly incongruous indices of health – to patients who are thoroughly demoralised. Meanwhile, patients are put in the exasperating position of having to justify the fact of their day-to-day experience of morbidity – and the decisions that are made on this basis – in the face of a highly authoritative set of imperatives that urge compliance. The challenge for all parties is to transform what is potentially (on the basis of these conditions) a situation of conflict and mistrust into one of effective support and communication.

Though a subject of much discussion in the context of the advent of HAART, 'compliance' has proved fairly unhelpful as a way of framing treatment issues for PLWHA in the context of significant side-effects and long-term effects, and interest in the topic has waned to a considerable extent. 'Compliance' creates a deadlock in thinking about living with HAART by being implicitly unable to fathom breaks from treatment for reasons that would otherwise appear perfectly legitimate (for example, those related to the shortcomings of the drugs). This is extremely unfortunate, for there is a level of awareness in the sector that preventing treatment resistance bears strongly on the long-term success of treatment, that the development of resistance is related to dosing practice, and that sticking to the regime is far from easy, or rarely 'comes naturally'. There is also a pressing need to invent ways of supporting those living with morbidity associated with long term use of treatment (whether caused by treatment or due to treatment failure). In this sense, the frame of 'compliance' could be identified as obscuring or distorting certain educational needs. Among these are the provision of those skills that enable people to live with treatment sustainably, evaluate different treatment events, and engage effectively with the scenes of medical practice. Indeed, in limited instances, the 'commitment' to HAART that 'compliance' requires may even be contrary to good health: for example, one of the doctors interviewed for this study reported much difficulty persuading a patient to stop therapy *despite* the emergence of endangering side-effects. In this report we talk in terms of developing a patient 'expertise on living with treatment'. This term is meant to register a more critical and active engagement with the discourses of health and medicine necessary to overall well-being, but also flags the importance of developing a reflexive stance on the many other domains of life *outside* medicine that bear on living with HAART, including

everyday embodied practice.¹ We propose that, beyond applying to adherence, this concept is a useful way of beginning to think about how to support those for whom treatment is failing. Cultivating patient expertise in turn requires the development of special expertise among HIV GPs. This is particularly pertinent given that chronic illness (as enabled by HAART) entails taking on more elements of the patient's lifeworld over the longer term,² and that general practice is the main point of contact with services for most PLWHA in Australia.

Of the many approaches to the patient's world we have encountered in this research, two general styles are worth outlining here. The first places a very high importance on adherence to HAART, and takes a proactive approach with respect to aspects of patients' lives felt to inhibit adherence. The second treats the patients' world more liberally, and tends not to take on matters that concern patients' lives beyond those amenable to medical solutions. Both of these general styles have advantages, and both have certain weaknesses. For example, while the first may appear overly intrusive, and sometimes dismisses the lived realities of treatment, practitioners who adopted it were more fluent in the historical, lived, and particular conditions affecting their patients, and had developed pragmatic techniques to help patients overcome some of these. Though the second approach accords much respect to the priorities and values of the patient, and may acknowledge the specificity of values that inform medicine, at times it can produce a reluctance to engage patients in evaluating or working on certain aspects of their worlds.

One of the most interesting ways this plays out is in relation to quality of life (see 'Negotiating Quality of Life'). In terms of the first approach, there is evidence that some practitioners are not entirely receptive to patient concerns (p.20). When this contributes to a felt lack of control on the part of the patient, there are dangers here. In terms of the second approach, by contrast, doctors' identification with their patients means that the priorities of patients influence practice to a considerable extent. It is possible, however, that in some of these encounters the patient's world is taken for granted, rather than explored. It may even come to seem inevitable. From our perspective, an expertise adequate to the task of living with HAART must enable PLWHA to evaluate, reflect on, and transform as far as possible certain aspects of their world so as to produce theirs as an experience of a particular quality. In this regard, there is much to learn from both of these general styles.

This report is divided into seven parts. The 'theoretical orientation' signals to other researchers, and those interested, the theoretical tools that have been used to make sense of these data. Those unfamiliar with social theory may wish to return to this section after reading the analysis. 'The problem-solution genre' outlines some of the key organising principles of the clinical encounter as they appear in recent literature. Two models of this encounter are identified as parameters that influence the ways in which HIV GPs have responded to the challenges of HAART. Throughout the report, we problematise these models, but also note that they are being problematised, implicitly and explicitly, in the practice of HIV GPs. The next sections analyse doctors' accounts in terms of some of the

¹ See Hurley, M. 2001 for an illuminating discussion of how community-based treatment media participates in broader cultures of care.

² Barry et al. 2001.

assumptions that appear about HIV patients ('The assumed consumer'); and how the patient's world can manifest through the lens of adherence ('The impediment to the solution'). 'Standard practice' in relation to adherence to HAART is described in the next section, with some attention to differences in these accounts. 'Querying stability' looks at how doctors assess patients' capacity to adhere, and explores some of the modes by which patients are involved in medical solutions that concern their lives. 'Negotiating quality of life' considers how doctors and patients negotiate the tension between science and what is important in the patient's life, again with particular attention to how different participants are authorised (or not) by forms of general practice.

METHOD

This research was designed as a preliminary investigation of communication between GPs and patients that bears on adherence to HAART. It comprises three data sets: one-to-one open-ended semi-structured interviews with HIV GPs; tape-recorded consultations between HIV GPs and HIV positive patients related to commencing, monitoring, or stopping HAART; and one-to-one semi-structured interviews with the patients involved in those consultations. This report focuses primarily on the first data set. *Compliance Supportive Communication* focuses on the second. The third data set was incomplete due to problems with follow-up. While the data from this third set confirms the findings of other research upon which we rely,³ it has been excluded from this report on the basis that it does not provide a strong enough means of evaluating the material in the second data set, the purpose for which it was originally intended. Additional data has been drawn from the HIV Health in Context study, a study conducted by the National Centre in HIV Social Research between 1998 and 2000.

Recruitment took place through a direct approach (phone and email) to GPs in Sydney who were licensed to prescribe HAART. Approaches were made to GPs with high and low caseloads, both inside and outside the geographic centre of the epidemic in Sydney. Doctors were offered a nominal sum (\$25) to participate in the first stage of the research, and one point in the \$100 prescribers programme for each stage of the research in which they participated. We were able to recruit 12 GPs to participate in a 1-hour face-to-face open-ended semi-structured interview, which was held in the practice of the participant. Two of these GPs (both high caseloads, located in the inner city) agreed to participate in data collection for the second stage of the research.

Of the GPs interviewed for this study, the majority (9) were high caseload doctors (>50 HIV positive patients) practising in the centre of the inner city area. Of these, six were gay male and three were female. Three GPs were low caseload doctors practising outside the city area. Of these, one was female and two were heterosexual male. All of the doctors interviewed had a majority of gay male patients, with four describing their caseload as 'almost exclusively' gay and others describing their caseload as 'mainly' gay, though with a

³ Race, K. and Wakeford, E. 2000.

small number of HIV-positive women, heterosexual men, and people who inject drugs. This reflects the epidemiology of the epidemic in Sydney.

The interview for the first section was designed after consultation with a number of key players in the field of positive education and treatments education. The purpose of the interviews with GPs was to gain some understanding of standard practice in relation to adherence to HAART, so as to contextualise the analysis of the second stage. Areas covered in these interviews included how the respondent GP made decisions about who would be offered HAART; how they assessed adherence and how this played into the decision to prescribe; their normal routine before prescribing HAART; how they monitored adherence; other techniques used to improve adherence; the sort of conversations they had about side-effects, long-term effects, treatment breaks and treatment fatigue; how much influence they felt doctors have over adherence; the perceived difficulty of adherence; and how they negotiated tensions between science and the patient's priorities. Interviews ranged from 30 minutes to 1 hour, with most taking the full hour. Interviews were tape recorded and then transcribed. After transcription, all identifying material was removed from the transcript. In this report, names have been changed, and identifying material removed, to protect anonymity. In the interview material reproduced here, the interviewers questions appear in uppercase and the participants responses appear in lowercase.

The accounts on which this report is based cannot provide a fully comprehensive description of what goes on in practice, and, as with all research, they supply only a limited representation of what actually happens. Nevertheless, the terms in which practice is described provide an insight into how practitioners think about what they do, and it is these terms that have been subject to analysis. As well as providing empirical detail, which occasionally influences practice, the intention of this document is to provoke thought, which might have further practical effects.

THEORETICAL ORIENTATION

This report provides an analysis of doctors' accounts of clinical practice as it pertains to adherence with HAART. It interprets these accounts as accounts of the government of patients. By government we do not mean the politics of the state, rather we adopt the sense of the term given by Foucault, to mean the deliberate strategies and techniques adopted for the 'conduct of conduct', that is, for acting upon the actions of others in order to achieve certain ends.⁴ Thus, in this case, we are concerned with the techniques adopted by doctors for the purposes of achieving 'adherence', and – more broadly – 'health and wellbeing', in their patients. The perspective of governmentality draws attention to the fact that the achievement of certain desirable ends, such as 'health', cannot be extracted from the exercise of power. Efforts to achieve such ends always involve efforts to discipline, regulate, or otherwise control individuals through the shaping of their conduct. Here, power is not understood as something that some people possess and use to oppress others, rather it is seen as permeating all relations, and can have productive and unanticipated

⁴ Foucault, M. 1991.

effects. This perspective allows a detailed understanding of the politics of situations usually thought to have little to do with power, helping to articulate the subtle ways in which control is exercised under the auspices of outcomes thought to be generally desirable.

Recently, attempts 'to act upon dietary and other regimes in order to minimize disease and maximise health' have been described as one of a number of political objectives that 'no longer seek to discipline, instruct, moralize, or threaten subjects into compliance. Rather, they aspire to instil and use the self-directing propensities of subjects to bring them into alliance with the aspirations of authorities'.⁵ This suggests that notions of the active individual are currently central to how certain social goals, such as health, are thought to be achieved. This view was confirmed in the accounts of doctors interviewed for this study, who conceived adherence as a problem of how to make patients sufficiently active, responsible, or committed, so as to carry out the demands of therapy.

What has become clear since the introduction of HAART is that there are ways in which the interests of authorities (say, for the purposes of argument, the viral suppression afforded by compliance) actually *diverge* from the interests of individual PLWHA (who may find that 'living well' involves, in some circumstances, a rational decision to take a break from therapy for a period of time). Against the idea of the active individual whose actions comply fully with the goals of authorities, it becomes necessary, in the interests of self-determination, to articulate another form of agency, one that can negotiate (and where necessary challenge) the subtle ways in which control is exercised in this domain. What is proposed in this report is that it is precisely this latter sense of agency that is necessary if one wishes to cultivate among PLWHA a sense of ownership and control over their lives that can have, as one of its happy side-effects, good adherence.

This latter sense of agency is commensurable with the theoretical perspective outlined, for as well as being capable of acting on the actions of others, individuals may act on their own actions for the achievement of certain ends. When made aware of how forms of power act upon them, individuals become capable of taking these as an object of knowledge, acting in turn upon them, forming a relation to themselves through which a choice is created regarding the ideals by which they might live. Rather than assuming freedom and choice, this view necessitates ongoing *practices of freedom*. In this report, 'ethics' refers to this sort of action upon one's actions, and should be distinguished from medical ethics (issues of confidentiality, consent, and so on).⁶

As has been suggested elsewhere, the capacity to reflect on one's typical embodied routines plays an important part in the incorporation of treatment into one's life.⁷ This appends the second theoretical perspective informing this research, which concerns the way in which everyday bodily habits give rise to a practical sense with which individuals negotiate the world. For Bourdieu, the acquisition of bodily gestures, comportment, habits and dispositions is culturally and socially specific, giving rise to a practical sense, in which

⁵ Rose, N. 1998: 160.

⁶ Foucault, M. 1994. For an illuminating discussion and application of this area of Foucault's work to drugs see Sybylla, R. 2001.

⁷ Race, K. and Wakeford, E. 2000.

one's culture and social positioning comes to seem obvious, self-evident, or natural.⁸ On this view, many of the beliefs of a culture and one's place in it are embodied - acquired and sedimented through habitual patterns of bodily activity - and are thus unconscious and obscured *as beliefs*. A familiar example of the operation of the *habitus* is the possibility of recognising elements of another's (for example a patient's) social positioning from their body and gestures (with all the risks of misinterpretation that any ill-informed reading implies). Our initial interest in *habitus* derived from the way in which it renders the presentation of personal 'competence' - seemingly an attribute of 'personality' - a matter of sedimented bodily practice, from gesture to everyday habits and routines. As we will discuss, such a move demands a revaluation of the typical ways in which the capacity to adhere is conceptualised and assessed, as well as the techniques used to improve this capacity. However there is a further implication in the relation of bodily practice to social structure that Bourdieu describes. The unconscious nature of the *habitus* infers certain barriers to the reflective and strategic development of an embodied practice, such as dosing. Doing work on one's embodied habits (say for the purposes of improving adherence) is likely - in some circumstances - to be a difficult and politically inflected act,⁹ for it must brave (perhaps in minute ways) the social practices that situate one as a particular type of subject/ reproduce a certain social order. (The dilemma confronted by PLWHA taking HIV medication in 'improper' places, such as work, is the most obvious example here, but others are worth considering. For example, a woman putting adherence before everyday domestic or childcare routines is a potential site of disruption to the social structure of the family, and may require some capacity to transform elements of this structure).¹⁰ Again, this calls for a form of agency that is not simply compliant with given beliefs and practices, but has the potential to negotiate the disruption it occasions.

Other theoretical perspectives will be outlined as they are employed in the report.

Accounts are analysed using a critical discourse analysis, which focuses on how the language adopted shapes social relations.¹¹ This method aims to uncover the assumptions embedded in particular accounts of practice, to see what is taken for granted within the culture (here, of HIV General practice), and what is being left out. The 'critical' component of this method is not levelled at individual practitioners, but at the discourses that produce practice. The critique made here is informed by, and provides a reflection on, the general values of equity, self-determination, and good health outcomes.

The term 'patient' is deliberately employed in this report to refer to the person living with HIV/AIDS in the space of General practice. This is intended as recognition of the power relations within that space, and is not meant to indicate principles that differ from those that underpin the PLWHA movement.

⁸ Bourdieu, P. 1990.

⁹ Bourdieu might say impossible. Unlike Bourdieu, we argue for a politically effective agency, drawing on Foucault's elaboration of 'practices of freedom'.

¹⁰ The 'simple' bodily act of taking medication may not seem to call for such a dramatic response, but when one considers this act may be accompanied by significant malaise, the act itself becomes less 'simple'.

¹¹ Fairclough, N. 1992.

THE PROBLEM-SOLUTION GENRE

The clinic is governed by sets of expectations, beliefs, and organising principles that frame both doctors' and patients' behaviour. A *traditional* model of the clinic has been expressed as follows:

The patient presents with a significant medical problem for which there is a potentially helpful treatment. What the doctor or other health care professional brings to the situation - scientific evidence and technical expertise - is classed as the solution. What the patient brings - 'health beliefs' based on such qualities as culture, personality, family tradition and experience - is classed by clinicians as the impediment to the solution. The only sensible way out of this difficulty would appear to be to bring the patient's response to the doctor's diagnosis and proposed treatment, as far as possible into line with what medical science suggests.¹²

The idea that the patient presents with a problem that it is the doctor's job to solve is a key organising principle in the clinical encounter. Broadly, it tends to frame how doctors in this study conceived their roles.¹³ In the above description, adherence is conceived as a problem of aligning the patient's 'health beliefs' with those of medical science. In this report we also refer to this formulation as 'compliance'.

The same source proposes what it conceives as a more 'liberal' and contemporary notion of the clinic :

The clinical encounter is concerned with two sets of contrasted but equally cogent health beliefs - that of the patient and that of the doctor. The task of the patient is to convey her or his health beliefs to the doctor; and of the doctor, to enable this to happen. The task of the doctor or other prescriber is to convey his or her (professionally informed) health beliefs to the patient; and of the patient, to entertain these. The intention is to assist the patient to make as informed choice as possible about the diagnosis and treatment, about benefit and risk and to take full part in the therapeutic alliance. Although reciprocal, this is an alliance in which the most important determinations are agreed to be those that are made by the patient.¹⁴

12 Royal Pharmaceutical Society of Great Britain, *From Compliance to Concordance: Achieving Shared Goals in Medicine Taking* 1997:12. This document is the product of a large working committee comprised of researchers and health care professionals in the U.K., and is selected as an approximation of the relevant literature. The document circulated in the Australian HIV sector in 1997 and 1998 and was widely discussed in sector discourse on 'compliance'.

13 One type of visit that is not so easily governed by this principle but is typical in HIV general practice is when laboratory tests are performed for the purposes of monitoring, or when the results of these are delivered and discussed with patients, as well as general check-ups.

14 *From Compliance to Concordance* 1997:12.

In this report, this description will be known as the *consumer* formulation.

The consumer formulation also assumes the problem-solution model of the clinic, in which the patient bears the problem, and the doctor possesses the solution. Here, however, the doctor's skills are portrayed as a commodity or service which patients can elect to make use of, by means of 'informed choice'. It is worth noting that here the doctor's role around what was previously termed the 'impediment to the solution' is diffused. The doctor bears less responsibility for working on or with the patients 'health beliefs', (coded as 'culture, personality, family tradition and experience'). Instead, it is the patient's task to convey these to the doctor, and (presumably) to dispense with them or entertain them according to the nature of his/her choice. The doctor's expertise (now demoted to 'health beliefs', although retaining the authority of being 'professionally informed') is conveyed to the patient in order to assist this process of choice. On this model, 'choice' is configured wholly in terms of the medical options.

These models provide some parameters for understanding the broad ways in which doctor-patient relations are typically conceived. The critical component of the analysis that follows questions some of the assumptions of these habits of thought, with a view to generating possibilities for thinking practice in ways that might better support adherence. While the accounts of practice collected for this study can be thought of as influenced by these broad conceptions of the roles of doctors and patients, it is clear that they, too, problematise these models.

THE ASSUMED CONSUMER

The doctors interviewed for this study typically stressed the importance of getting to know the patient over time, and portrayed the process of prescribing HAART as one that occurred over a number of visits. The issue of how to make patients involved in decision-making, and acquire a level of responsibility (or ownership) around treatment was a key problematic with which some practitioners actively grappled, and one that was used to think about and modify their own practice. In some instances, however, patient responsibility featured as a presumption that was used to demarcate the bounds or limits of the space of General practice. It is difficult to get a sense of how this plays out in practice, and the flexibility of GPs with regard to the singularities of patients' circumstances is acknowledged. However, there is some evidence to suggest that an uncritical adoption of the consumer formulation may presume a particular level of patient competence, and exclude (or render trivial) certain sorts of knowledge.

Jim, a high caseload gay GP working in Darlington with mainly gay male patients, said:

I mean I think nowadays most people who have been HIV for a while are very well educated. At least the ones I see. They're very intelligent. They read updates all the time and they know it as well as you do. So, the decision making for them anyway it's more like it's the shared thing. The decision making is not what you think; it's what they think. Superimposed on what you think is the best choice. So, you know, it's about empowerment, you know. My personal theory and style is I like to empower because I think about what would I like myself. That may not work for some others. Because I know a lot of doctors where people just turn up and they'll tell you what to do, you'll do it or you die, sort of thing. Whereas I don't. So, I treat them as though they are sentient beings with intelligence and they can sort of choose what will suit them best.

Here, room is made for considerations from the patient's world, but there is an uneasy tension. These principles seem to run the risk of presupposing a certain proficiency in medical knowledge, and envisage a particular level of self-sufficiency among patients. Angela, a high caseload GP working in Darlington, with mainly gay male and some female patients, stated:

...I guess one of the things that I carry ... is an awareness that patients actually choose their own therapies and choose whether they take their therapies or not. That the patients determine their treatment and that my aim when I'm trying to look after patients is to help them in the choice of what I would regard medically as an appropriate treatment for them. But not to be prescriptive about how I tell people about giving - give people information. I don't tell people to take tablets. If they ask my advice I give them advice and I'm happy to provide appropriate guidance for people, but I'm not the sort of doctor who will say, you must take this because such and such and have no negotiation. ... people can - will choose - the reality is people will choose what suits them and my aim is to guide them in their choice and to help them make sensible choices and to help them maintain their treatments.

Later, in response to the question on how much influence she thought doctors have over patient adherence, she replied:

Over patient adherence, yeah well I think there's - yeah, the one thing, I think, is patients will only take what they - will make a decision, and if they believe in the treatment they'll take it. I think, I mean, if I mention it every time that they come in then that's a prompt for them to remember that that's important. Everybody needs a bit of prompting with their routine things. So, I think to a certain extent we have got - I've got a duty to remind patients, but I don't think - if the patients don't believe in the treatment, I think that if the patients don't believe in the treatment they're not

ever going to take it. So, I think that while I can help remind people it's their story about taking the tablets. People are adults and of course it's their responsibility.

IS THERE ANYTHING ELSE YOU'D LIKE TO SAY ABOUT HOW YOU DEAL WITH THE TENSION BETWEEN WHAT MIGHT BE SCIENTIFICALLY BEST AND WHAT MIGHT BE BEST IN TERMS OF THE PATIENT'S LIFE OR THEIR LIFESTYLE OR —

Okay, I talk to them about that, yeah. I think it's - I'm a doctor treating patients, it's my prime thing that I do and um I like to give people the best medical evidence of what to confirm that what I'm doing is the right thing for them or what they're doing is the right thing for them. So, I like to be able to give them the scientific data to back up what I would like them to do.

This raises some of the key tensions that run through these data. The doctor's scientific expertise gives her some sense of a preferred course of action (*'I like to be able to give them the scientific data to back up what I would like them to do'*), yet her practice is framed in the language of informed choice. Thus she withdraws from 'being prescriptive'. Though she may hold and express a scientific opinion, there is some equivocation about whether her role extends to intervening in issues of 'lifestyle' and 'beliefs'. As in the second model above, these latter issues seem to be consigned to the patient's domain of responsibility. She understands her practice as a service delivered to self-electing consumers, who are free to choose an appropriate course of action.

This attitude accords with broader neo-liberal, pluralist understandings of the citizen's relation to authority. As discussed above, political objectives no longer seek to moralize subjects into compliance, but attempt to use the 'self-directing propensities of subjects to bring them into alliance with the aspirations of authorities'.¹⁵ As Rose mentions, this can result in the marginalisation of those who do not exhibit such self-directing propensities.¹⁶ Further, it depicts the latter eventuality as a straightforward matter of choice among the relevant individuals and groups.

The language of individual choice may be thought to make good sense in the context of uncertainty and a plurality of scientific opinion, especially given the critique of paternalistic medicine made by various groups over the last four decades (including AIDS activists, women's health groups, and adherents to alternative therapies). However, this formulation of doctor and patient responsibilities bears the potential to create significant gaps in care, as some doctors interviewed for this study recognized. A particular level of education and competence is often assumed. In addition, it is worth considering that 'choices' are always made within particular parameters and contexts. The perceived lack of choice around elements of one's own world may compromise in substantial ways any participation in the sort of choice being offered here.

¹⁵ Rose, N. 1998:160

¹⁶ With Rose, we note that programs directed such marginalised subjects (such as 'work for the dole', or in this context, 'goal-setting' initiatives such as the Reconstruction project) employ a very similar vocabulary and image of who the subject could and should be – that is active, autonomous, choosing.

It is a key finding of this section that in the circulation of consumerist understandings of the doctor-patient relationship, some doctors' perceived roles around what is here termed the patient's 'health beliefs' ('culture, personality, family tradition and experience') have transformed and, to a certain extent, diminished. Often, the patient's 'health beliefs' are seen as being outside the domain of General practice. This may be entirely acceptable, indeed preferable, for the self-reliant, highly autonomous patient. Some PLWHA are more than capable of thinking through their own experience as it pertains to adherence. Other patients may need more assistance.¹⁷ The conceptions of doctor's roles found here seem subtly to preclude patient expression of, and doctor involvement in, such matters. If 'the task of the patient is to convey her or his health beliefs to the doctor; and of the doctor, to enable this to happen', these examples suggest that there is room for a more pro-active role in the latter.

We propose below that opportunities for PLWHA to reflect on how identity, lifestyle, experience and values bear on treatments (and treatments on them) might better equip PLWHA to make the relevant decisions, and to develop and carry out solutions. This idea, which we will develop as 'a patient expertise around living with treatment', requires the support of doctors and other bodies, and not the assumption that people can just do it for themselves (though some may). We shall investigate the practices that encourage the development of this patient expertise in General practice, and those that impede it. What is clear from the above discussion is that some habits in the way the clinic is thought do not simply presuppose a certain level of competence among patients, but may actually render trivial or insignificant certain forms of information that may be relevant to developing this patient expertise.

THE IMPEDIMENT TO THE SOLUTION

We have observed that the adoption of consumerist understandings of the clinic has the effect of devolving some of the tasks formerly associated with General practice (specifically working with patient 'health beliefs') outside this domain, creating the potential for inequitable health outcomes. However, many doctors interviewed for this study did recognize that the problem of adherence to HAART called for extra attention to how medical solutions were handled. As Clive, a high caseload gay GP in Darlinghurst with a mixed caseload, suggested:

¹⁷ In this respect, recent research (Barry et al. 2001) has identified good outcomes when (1) both doctor and patient choose to use the voice of medicine exclusively [consumer model], or (2) where both doctor and patient engaged with the patient's lifeworld. Poorest outcomes occurred where (3) patients used the voice of the lifeworld to frame their problem, but were ignored or blocked by the doctors' use of the voice of medicine. This latter type of consultation tended to be witnessed in cases of chronic illness. Such consultations are described as those where 'the doctor was trying to move the consultation towards closure while the patient was trying to bring the doctor back to the stage of identifying and defining the problem' suggesting 'the reason the patient might have felt their problem had not been sufficiently defined was because of the exclusion of the lifeworld'. This research does allow for the possibility of consultations where both patient and doctor are satisfied with relating in the voice of medicine (1), as the consumer model envisions, (though it is suggested that part of the reason for this may be that patients may have learned that the lifeworld has no relevance or welcome place in the consultation). The researchers emphasize the need for structural reforms to provide a suitable framework for care that engages the patient's lifeworld.

Well, that's the aim of general practice, I guess. I mean HIV GPs are sort of in that area between science and um the - hopefully know patients very well and that's the nice thing with general practice, is that you have to try and marry up scientific knowledge to the psycho-social situation of the person. And I mean I often see things where a patient I know very well has ended up at [a hospital] and one of the specialists has decided they're going to do blah, blah, blah with them and they come back here and I know that it's not going to work out because I know the person very well. And the specialist's only met them once for ten minutes and suggested doing something, which I think is definitely not going to work. And I think it's very interesting because technically they know more than we do, but they don't know the patient nearly as well as we do.

So, they'll make the, I think the technical error - I mean more the psycho-social error I should say. Whereas in general practice we may make technical errors because we don't know the science as well, but I think the outcome may be better because we know the person. Which is a luxury, I suppose, of knowing a person very well.

It is revealing of the constraints on practice that even in Clive's terms, expertise pertaining to knowledge of the patient is classed as a 'luxury', despite the recognition of its role in better outcomes. In this section we develop the idea that treating HIV is a technical problem in which the 'one who controls is the one who determines how the technical problem will be posed and notably if and how it will take into account constraints determined by human values and interests'. (Here, we note that 'lack of control' is precisely that which many PLWHA report when describing the difficulty of adherence). The type of technical definition brought to bear on the problem is a matter of 'the type of experts recognized as legitimate spokespersons in the discussion'.¹⁸ Following Stenger, we would like to put the view that the sort of error that this GP claims specialists are prone to is in fact a *technical* error, in that it does not incorporate the full range of knowledges that bear on adherence (for example, experience/expertise relating to the patient's lived world). It is a solution to a problem badly formulated.

A number of doctors did refer to 'beliefs', or the patient's 'perspective on treatment' as something that could affect adherence. Judy, a high caseload GP in Darlington with predominantly gay male patients, offered one of the most detailed understandings of how certain 'psychosocial' and historical contexts are affecting treatment:

We've certainly seen a number of patients here - oh sorry in a group, a sub set, not in certainly the majority, by any sort of means, you know, but people who have been positive for a very long periods of time who essentially have not created any life outside of that, you know, um they've been on pensions for a long period of time and that may be up to a decade or more. And with the drugs making them well enough, you know, in the beliefs that they're working on really well, um, have to then start to

¹⁸ Stengers 1997: 218

recreate some life and we've certainly seen huge amounts of problems for people working that through. To the point where a number of them have created problems with their drugs, yeah. I don't think in any conscious way, but I think certainly in a subconscious way to again —

SO, THE DRUGS

Well, I think - I think, um, either the drugs get given some sort of negatives, that then they've got to stop, and in some way then get viral load back, you know and then that's a way to focus on their health again...

As discussed earlier, the task of working with these broader circumstances of experience and identity, that in turn frame beliefs about treatment, may fall outside the domain of General practice when it is understood as a service for consumers. By contrast, in Judy's general account, these patient circumstances feature as an 'impediment to the solution', as in traditional conceptions of the clinical encounter. This raises a difficult issue. While contextual detail is offered in this description, patient circumstances are understood as problems of individuals. In a more extreme form, the discourse adopted here could infer that issues of choice are false, or that patients who refuse medical advice are abnormal or in need of psychological correction. The question arises, how are these aspects best addressed, and – further - what is the appropriate exercise of authority in relation to the patient's world? While Judy's more pro-active style makes visible what might be being left out of General practice on the consumer model, are we to accept the identification of patient health beliefs as a 'problem' to be resolved by the doctor (or other professionals)?

These questions relate to an important feature of doctor-patient interaction. When, in accounts of General practice, what Clive calls the 'psycho-social situation of the person' is registered, it tends to appear in terms that repeat the traditional distribution of roles and responsibilities in the clinic. That is, it appears as a problem that must be fixed (or allowed for) by the doctor, and upon which the doctor is the authoritative source of knowledge.

A different instance of this appears in the account of Edward, a high caseload GP practising in the inner city, who refuted the consumer model of General practice. In his reasoning he acknowledged the differential skills of patients, and stressed the importance of getting to know the patient.

Oh I think we have a big influence [over patient adherence] and um I think it's important that that's the role of medicine now. It's all very nice to say that we as GPs are expected to provide the patient with informed consent and provide them with knowledge, but that is not a fair perspective. Not from a GP's perspective or the patients', because the patients cannot understand everything about drugs. They are looking for a GP to advise them and advice is not often based purely on fact. But the GP tries to advise on the basis primarily of fact, but it's also sometimes on things apart from fact. That is feelings, opinions, predictions.

SO, YOU'RE SAYING THAT REALLY THE PATIENT ISN'T UM YOU CAN'T EXPECT ALL PATIENTS TO HAVE THE SORT OF COMPETENCE AROUND MEDICAL KNOWLEDGE ... LIKE I'M THINKING OF UM YOU KNOW THAT LINE THAT UM IT ALMOST SORT OF CONCEDES THAT THE DOCTOR/PATIENT RELATIONSHIP IS THIS REALLY CONTRACTUAL SORT OF THING, THAT UM – I MEAN YOU'RE SAYING THAT PATIENTS COME TO YOU LOOKING FOR ADVICE FROM YOUR KNOWLEDGE BASE?

Yes, they're not just looking for knowledge; they're also looking for advice. Forever I'm getting patients saying; 'well what do you think I should do?' I present them with the information. I say well these are your options. Option one, option two and they'll just still look at me and say, 'well, what should I do?' In other words, you know, bugger the advice I just want you to tell me. You know, and that's the reality of decision making in this, you know, process.

AND SO WILL YOUR DECISION IN THAT CONTEXT BE PURELY A MEDICAL ONE OR WILL IT BE ALSO BASED ON SOMETHING —

It won't be purely based on facts and figures because there is no - because often the facts and figures don't give you 100 per - won't give you a definite answer. I will also base it on some of the gut feeling about say the adequacy of the treatment for them and their ability to take it and uh timing. That now is a good time. Yes, so there will be those sort of fluffy elements around the decision making process.

AS A WINDOW INTO THE PATIENT'S LIFE DO YOU THINK THAT THE CONSULTATION IS - CAN GIVE YOU SOME SORT OF GOOD ENOUGH GUT FEELING AROUND THAT?

Well, good enough is a sort of ambiguous term. I think that you could spend - the aspects of general practice is that it's time based and has to roll over fairly quickly. I think if you spend more time with patients you could get better insights. Maybe if you had more feedback from some of the allied health professionals that may help you get an insight. But as I know that doctors are poor predictors of compliance I really wonder if spending more time with the patient still would necessarily help you decide who was going to be able to take the medications and who was not. I just don't know that answer.

OKAY, IS THERE ANYTHING ELSE YOU WOULD LIKE TO SAY ABOUT HOW YOU DEAL WITH UM I GUESS THE TENSION BETWEEN WHAT MIGHT BE SCIENTIFICALLY BEST AND WHAT MIGHT BE BEST IN TERMS OF THE PATIENT'S WORLD AT A PARTICULAR TIME?

Yeah, I suppose one of the big issues is that to introduce uncertainty with some patients is a very negative force. Some patients really need a sense of certainty and structure, which doesn't actually exist in reality. But, you know, they come to a specialist because they want a sense of certainty. They don't deal with um uncertainty very well. They become very anxious and it's very disruptive for them.

We have to tailor our approach according to how we see the personality of the patient and I think that's the bonus of a long term relationship with patients in general practice and choosing medications on the basis of that.

Here a flexibility of techniques is mentioned ('we have to tailor our approach'), suggesting clinical practice is much more contingent and circumstantial than a straightforward application of the science, for elements of the patient's world must be taken into account. While the importance of getting to know the patient is discussed, the indeterminacy of such knowledge is acknowledged. A directive role is favoured to accommodate for the differing capacities of patients. As is made clear on this account, this role tends to gloss the uncertainties in clinical knowledge. Again, we might understand this as a more 'traditional' approach to practice, made in the context of the range of patients and time constraints.

In terms of the above discussion, what is interesting about this discourse is how a certain level of authority is assumed by the doctor around the 'fluffy elements' ('*the gut feeling about say the adequacy of the treatment for them and their ability to take it and uh timing.*'). One effect of this, in the last paragraph cited, is that the shortcomings of HIV science become defects of patient personality.¹⁹ The question arises, what is being protected or contained in more 'traditional' approaches? (Here we note that both doctor and patient may assume this approach). Might the (well-intentioned) kindness to the patient withhold or preclude a more political or active engagement with the medical field on the part of people living with HIV/AIDS? If this seems like a far-fetched ideal, a more pertinent (but not unrelated) concern is how this assumption of authority may work to impede the authorisation of the patient in terms of her/his life. That is, in assuming a level of authority about the patient's world, it withdraws from efforts to improve the patient's capacity to know and act upon that world. Yet the difficult work of authorizing the patient may be precisely what is needed to promote the development of patient expertise on living with treatments.

Two further considerations militate against the continued representation of the patient's world as the 'impediment to the solution'. First, a reversion to traditional paternalistic understandings of the doctors' role is inappropriate in a liberal democratic context. The acknowledgement of different values in relation to medicine, and the principle of self-determination, have historically been, and continue to be, germane to the field of HIV/AIDS. Classing patients' health beliefs as an 'impediment to the solution' instates a traditional conception of medical authority, ignoring the fact that at any particular time medicine (or a particular medical discipline, such as virology) may value specific aspects of life that differ from those that particular patients value.²⁰ This segways into the second consideration, which relates to the continuing uncertainties in clinical knowledge regarding the long-term management of HIV treatment, and the substantial inadequacies of the

¹⁹ We are grateful to Niamh Stephenson for this observation.

²⁰ At a recent PLWHA conference a delegate commented that longevity was not the most salient feature of life for many of his positive friends. This comment does suggest how 'hit hard, hit early' might have been experienced (and resented) by many as a moral mandate – particularly in the context of the lived difficulties of treatment, though it would be unwise (indeed dangerous) to universalize this claim to all positive people.

treatment itself. It is unknown what patterns of treatment (whether continual or intermittent) will produce the best results over the long term. Also, while capable of substantially prolonging life, HAART is known to cause a range of health problems, and is likely to have other, currently unknown, effects. In such a context, it is both unreasonable and unrealistic to expect PLWHA to submit their lived experience of treatment to the attainment of abstract long-term goals as determined by medicine, where this experience compromises their quality of life in substantial ways. Yet if the patient's world is depicted as an 'impediment to the solution', this is precisely what is implied.

These considerations recast the way in which the patient's world might feature in the thinking of clinical practice, such that it can no longer be constructed as an 'impediment' that the doctor corrects, but becomes instead an essential reference point in the technical formation of 'problems' and 'solutions'. They propel attention to the question of how patient expertise might be developed. The emphasis here on *developing* patient expertise is intended to redress the oversights and assumptions of the consumer model, as discussed above. This expertise would not consist entirely in medical knowledge, rather it must be capable of making considered evaluations of treatments and their world and how each bears on the other, authorizing the patient to set the terms according to which a solution's success is measured. It might aim to develop an understanding of the material constraints of a patient's situation in such a way that the patient (perhaps through enlisting the help of others) can act upon these.

The following sections develop these ideas in relation to two broad areas. First, we look at how some of the causes of adherence and non-adherence are thought about by doctors, with attention to how authority regarding the patient's life is distributed in relation to the technical solutions employed. Second, we examine how discourse on 'quality of life' can resituate the respective roles of doctor and patient in the formation of problems and solutions. Both of these involve issues of how, through what sort of practices, a sense of patient agency or autonomy is produced. In this sense they have a direct bearing on adherence.

Before this, we outline the typical approach to adherence that can be discerned from these data.

STANDARD PRACTICE

To the extent that a standard practice has been developed to address adherence, it might be described as follows. For the most part, it converges around 'preparing' the patient. A number of doctors referred to what one doctor called a 'grey zone', between 500 and 350 T-cells, in which the idea of HAART would be introduced. This 'grey zone' was constructed as an opportunity to increase the patient's capacity to adhere, and a number of techniques are employed to this effect. These include providing the patient with medical information on the drugs; providing other printed educational resources; discussing the patient's lifestyle (usually in terms of 'tailoring the regimen'); referring the patient to other professionals or services (including specialists, treatment officers, counsellors, psychologists); and suggesting the patient talk with HIV-positive peers. Typically, the

objective expressed here was to ensure that the patient formed the correct resolve to go on therapy, or was capable of making a 'commitment' to therapy. Some doctors suggested that they needed to be convinced of this commitment before prescribing HAART, to prevent harm (in terms of treatment failure and viral resistance). None indicated they would absolutely withhold treatment failing this, or after attempts to increase a patient's perceived capacity to adhere had failed.

A second set of practices employed here related to 'monitoring', where doctors saw themselves as having a role in 'reinforcing' adherence by 'reminding' patients, normally by asking them how many times they had missed doses.

Among lower caseload doctors, the above activities were usually perceived to be the province of the prescribing specialist.²¹ Among all the doctors interviewed, different levels of emphasis on the importance of these techniques were apparent, with some appearing to limit their role according to how they assessed the likelihood of adherence for the patient concerned.

There was however implicit and explicit criticism, both of the idea of a 'grey zone', and the way adherence is addressed in monitoring practice. Occasionally a more 'pre-emptive' role was envisaged that could tackle the ways in which adherence is impacted by changes in the patient's world. One doctor refuted the idea that there is

...some sort of, you know, degree of competence you get them to and then they're can sort of go off driving on their own. And I think I said it's exactly the opposite, that they constantly need that support and constantly things are changing...

In contrast to typical monitoring practice, the technique adopted by this doctor involves asking the patient what *situations* have been difficult for adherence, and actively working with the patient to find solutions to that situation. The intention here is to enable the patient to build a capacity to minimise the chance of that situation recurring - or the impact of it if it does. This different approach draws attention to one of the assumptions of the standard practice of preparing the patient then monitoring, namely that it relies on notions of competence that, once achieved, are viewed as needing minimal ongoing engagement.

In the next section we consider how doctors assess the likelihood of adherence, or 'competence'. As we have mentioned, this assessment appears to influence the extent to which efforts to improve a patient's capacity to adhere are pursued.

²¹ One mentioned the need to link patients into existing services and resources in circumstances where the patient did not have a peer network they could draw upon.

QUERYING 'STABILITY'

When doctors were asked how they assessed the likelihood of adherence in a patient, the concept of 'stability' frequently emerged. This tended to be understood in terms of 'conditions of the self'. For example, Jim stated:

As I said I always look at the person and I make some sort of value judgment on how they would adhere. And, you know, I just - I can't generalise, but I just think some people, you know, I think people who are very stable and have sort of happy fulfilled lives have a lot to do with good adherence. Because they don't find everything else an issue. People who are - have a lot of issues, a lot of chronic conditions of the self, would find it more difficult because there's a lot of other things going on in their lives.

SO, WHAT SORT OF THINGS WOULD YOU LOOK FOR WHEN YOU'RE THINKING ABOUT STABILITY?

Well, you know, things like employment, relationship, whether or not they're happy, not depressed, you know, a lot of people I think have a background of depression. Just - or lack of self-esteem. I think a lot of those things have to be fixed and part of, you know, what we're doing here at the moment by deliberately getting a counsellor and dietician is that I also find having different voices to tell them the same thing is also important.

For some doctors, depression was a generalised phenomenon in their caseload, related specifically to the social disadvantage faced by gay men in terms of social isolation, alienation from the family, and associated drug and alcohol use. While just over half of the doctors interviewed mentioned 'depression' as something that influenced their assessment of whether a patient would adhere, it was often unclear whether aspects of the personality, or certain material contexts, were more prominent. In other words, 'in/stability' was sometimes attributed to personal characteristics, and sometimes to fluxes in employment, relationships, and other material contexts. The latter cluster of factors could range from broad social conditions to more immediate circumstances, and in this respect were often denoted by the term 'lifestyle'. When asked what he took as signs of an 'orderly' lifestyle, one doctor replied:

Um regular job, regular place to live, um you know, sort of stable interpersonal relationships, you know maybe a regular partner; and again another thing you get a feel for in general practice, you know, whether they're sort of leading that sort of life and I know occasionally you sort of were way off the mark, but I think generally you get that sort of feel.

The constant slippage between an understanding of 'stability' as a 'condition of the self', and one in which it referred to more contingent features of a 'lifestyle', may indicate a

conceptual need to give some account of circumstantial change in patients' material situations. Despite this recognition, the lens through which these conditions were apprehended was inclined to retract back on to the individual. For example, external pressures tended to be transposed into 'conditions of the self' through ideas such as 'coping':

Lifestyle may play a role. I'm just trying to picture myself in a situation where I was speaking to somebody. If they were having a lot of troubles at the moment which were causing them some distress. If they were having a lot of pressures on them at the moment and they were having difficulty coping I certainly would suggest that we shouldn't introduce taking medications as yet another stress, right now. We should introduce it at a time when they feel like they're more stable.

Here the patient's situation (denoted by the verb 'have' in relation to 'a lot of troubles') is converted into a personal characteristic (denoted by the verb 'be' in 'they're more stable') via the mechanism of 'coping'.

The in/stability of a patient's circumstances, as revealed in conditions of habitat, employment, and relationships, was registered at an even more basic level for some doctors – specifically, through an inquiry into the patient's bodily habits. Philip, a gay male high caseload *doctor*, asks:

Are their hours regular? ... Do they normally eat breakfast? So, I try and establish good eating habits before starting the drugs, and I think that's really important because a lot of inner city people don't have good eating habits at all, are not regular. So, it helps if they're gym queens because, you know, they've got a nice regular um dietary intake happening already and they're usually eating plenty of meals a day. But I think building them up constitutionally with exercise, regular sleeping habits and regular eating habits, just the common sense your grandmother would give you before starting the drugs is a really good idea. So, those general health issues I hopefully have addressed long before the time to actually start taking the pills. Then we talk about how they're going to do it and if they're shift workers and stuff like that and that's why I'm very flexible about as long as it's twice a day, they don't have to be setting an alarm clock twelve hours apart, and I try and choose regimes where that's not crucial.

In the above passages it is clear that doctors use a range social indices to assess 'stability', from basic bodily routines and habits to broader surrounding conditions and circumstances. Since we have suggested that some acknowledgment of differential skills and capacities must be made if equitable health outcomes are to be achieved, no strong objection can be raised here, beyond the possibility of error.²² However, in general, one is

²² It does appear to be the case that adherence discourse tends to privilege a very particular social actor (middle class and self-contained). This has some exclusionary effects, in terms of when treatment is prescribed, but this (continued)

left with the impression that this manner of assessing patients has the effect of leaving middle-class attributes and dispositions unproblematised. Indeed, for some doctors, 'stable lifestyles' emerged as a theme only in terms of its other – 'chaotic' or 'erratic' lifestyles. This referred to a conglomerate of issues that seemed to include depression, drugs and alcohol (particularly drug injection), and 'itinerant' patterns of living, often bearing class connotations. The effect of this optic is to create a division between needy, maladjusted, unstable individuals, for whom special measures are needed;²³ and competent, adjusted, stable individuals, for whom adherence is assumed to be unproblematic.

The topic of illicit drugs created a space in which some of the above assumptions were queried. As a bodily practice imbued with volatile effects, its perceived (or disputed) interplay with material circumstances created ambiguities in the assessment of in/stability. When asked to say more about what was meant by an 'erratic lifestyle', one doctor replied:

Um if they're home situation is unstable. Like they don't have a permanent place to live or they're in the process of moving. If they uh um have a sort of history of sort of um changing jobs a lot or if they've been using drugs and um if they're sort of a bit haphazard about turning up for appointments and things like that.

RIGHT. WHEN YOU SAY USING DRUGS DO YOU MEAN INJECTING DRUGS OR JUST USING DRUGS GENERALLY OR —

Um I think its more using drugs on a regular basis.

DO YOU HAVE SOME PATIENTS WHO DO USE DRUGS AND ARE ALSO 'PEDANTIC'?

Um uh I don't think the two um are compatible in the same - so I guess people may be pedantic, but I think if they start using drugs their life becomes a bit more chaotic.

Other doctors questioned the straightforward equation of 'chaotic lifestyle' with the use of recreational drugs. For example:

WHAT ABOUT UM CHAOTIC LIFESTYLES LIKE DRUG USE?

I'd say the majority of them use recreational drugs at some stage. In terms of chaotic I think that's a - I would say that some of them have chaotic - they fall along the spectrum of chaotic lifestyles up one end and that's the chaotic end, yes. There's quite a few of them who would.

temporary exclusion seems to function as a strategy to address the capacity of adherence in various ways. A number of doctors said they would prescribe HAART to patients who were unlikely to adhere, citing some clinical benefit.

SO, ARE YOU SAYING THAT THERE'S SOME RECREATIONAL DRUG USE WHICH IS NOT PROBLEMATIC AND SOME WHICH IS MORE?

I would say that there is some - yeah, I'd say recreational drug use may go hand in hand with chaotic lifestyle, but one doesn't mean the other.

RIGHT, OKAY. WHAT ELSE MAKES UP A CHAOTIC LIFESTYLE?

There's lots of reasons why people have chaotic lifestyles and that is their personality. Stresses and strains, events, issues that have arisen. Um partner relationship issues. They're the - so, psychological factors and drug factors would both cause chaos.

When asked what she considered when assessing the likelihood of a patient's adherence, another doctor replied:

Uh inability to keep appointments. Strong correlation across to inability to conform to a regimen. Chaotic lifestyle, you know, not necessarily in terms of um other drug use, but just chaotic lifestyle ... People can be just as chaotic if they're an incredibly well paid executive as opposed to, yeah. Um major amounts of alcohol use, ...um pre-existing depressions...

In some of these passages, the usual indices of 'stability' are queried. In other instances, these indices are used to distinguish between recreational drug use that is problematic and that which is unproblematic for the purposes of assessing likely adherence (for example one doctor drew a distinction here between competent and 'messy' patients). In still others, such differences are explained in terms of personality.

Taken together, these data draw a complex and potentially dynamic picture of the relation between *personality* and *life circumstances* – between *being* (personality, individual competence) and *having* (ranging from embodied habits to habitat). That is, they bear an insight that *who* one is may not be extricable from what one has and does - one's embodied set of dispositions, and the resources one has at a given moment, or has acquired over time. But perhaps more interestingly, they suggest that the recognition of a middle-class bearing as a sign of adherence is less than adequate. Given the unavoidable flux in material conditions, what may be more important than the cultivation of a predetermined set of bodily habits is the capacity for a critical and reflective relation to these. Despite this, in only a few instances did doctors portray themselves as having an active role in assisting the patient to work upon embodied habits, by means of helping them to constitute these as an object of knowledge, that is, as a domain of actions that might be modified. This suggests that, for some practitioners, 'lifestyle' features as a given, beyond the scope of doctors' (and implicitly patients') influence.

23 One doctor mentioned the use of a community nurse and directly observed therapy in this context, another (continued)

In this regard, two broad roles are available for the doctor. The first consists in regarding the patient's 'instability' as a problem that must be 'fixed' by the doctor for the purposes of adherence, as constructed in the passage quoted at the start of this section²⁴. The second emphasizes the ongoing development of a patient expertise on living with treatment, in which the patient is assisted to take their world as an object of reflection and potential transformation. The latter encompasses the crucial work of developing with the patient an understanding of their world in such a way that it presents a choice, not simply about which medical options to pursue, but concerning the material and lived constraints facing the patient that inhibit adherence, and – more broadly – wellbeing.

In earlier sections, we began to look at how the patient's world materializes in the context of an increased emphasis on adherence. Since it appears as an 'impediment' most appropriately tackled by the doctor, it is usually elicited in a manner that depends upon the technical solutions that doctors feel they have at their disposal. In the context of growing pressures on efficiency and time, such solutions are increasingly limited. Here Bijker's idea of a 'technological frame' may be useful. Technological frames specify 'what counts as a problem as well as strategies available for solving the problems and the requirements the solution has to meet'. They 'further serve to structure the interactions of members of a social group'.²⁵ Understanding the range of issues connoted by the term 'stability' in terms of depression renders them amenable to the technical 'solutions' available to the doctor. While Jim mentions counselling and dietician services, this list is also likely to include antidepressant medication, potentially giving rise to a situation in which a patient is prescribed more pills for the latent purpose of better adherence to those already prescribed.²⁶ If adherence has invested the topic of depression with extra significance in HIV general practice, it is striking that this materialization of solutions potentially compounds the difficulty of adherence.²⁷

This is not meant to deny that there are genuine cases of clinical depression, or that there exist situations in which anti-depressants may be useful. Rather, we wish to draw attention to how certain forms of relating to the patient, and encouraging patients to relate to themselves, are inhibited in this technical framing of the problem. The presence of antidepressant medication (as a technical solution) might be shown to frame problems of adherence in terms of 'depression', despite the common recognition that something more complex might be going on, (as discussed above). Meanwhile, more intensive and open-

spoke of the need to increase attention a patient's adherence whenever antidepressants were prescribed.

²⁴ Here we acknowledge that the accounts collected here (such as the passage quoted at the outset) may not be a rigorous representation of what the practitioners actually do in practice, however we hope that the analysis offered provides conceptual tools that will be of use.

²⁵ Bijker, quoted in Banks and Prior, 2001.

²⁶ The account of Barry, a gay high caseload GP in the inner city, gives some insight into one way antidepressants feature in practice. Interestingly, his account involves an explicit questioning of the straightforwardness of categories like 'depression': "WHAT ABOUT SOMETHING LIKE UM DEPRESSION? If they were depressed - if they were depressed and that was impacting on them and they weren't functioning, then, yes. I think depression per se is not the issue. If somebody presents to me with depression and a need to start medications I would probably want to deal with the depression first. If I couldn't, if they had an ongoing depression that doesn't really respond to medications but it wasn't interfering much with their life then I'd still go ahead with the medications. I don't think depression necessarily precludes good compliance."

²⁷ While 'number of pills' is generally not thought to be predictive of adherence, in the Positive Health study, among those people who were taking any prescribed pills, 21% reported that it was somewhat difficult or very (continued)

ended ways of eliciting and responding to the patient's circumstances, and developing the patient's capacity to act upon those circumstances, may come to be positioned as outside the core work of general practice.

Another example of this distinction exists under the rubric of 'tailoring the regimen'. Interestingly, the problem that the patient's world represents within the discourse of adherence is now being encapsulated in terms of product design, with the development of new products like Trizivir, comprising three old compounds contained in one delivery system, engineered specifically for the purposes of making adherence easier.²⁸ While for some doctors 'tailoring the regimen' consisted in an almost microscopic discussion with the patient of the most basic of bodily habits, for others, this amounted to 'prescribing simpler regimes'. In the account of Philip, observe how these competing solutions seem to moderate each other:

DO YOU TALK ABOUT THEIR LIFESTYLE AT ALL?

Oh yeah.

WHAT SORT OF THINGS ABOUT THEIR LIFESTYLE?

Are their hours regular - I don't prescribe any combinations that aren't twice daily. If it's more than twice a day then it's no good. Sure, later on that might be an option, but that's when people have burnt up a lot of options and then they're going to be, I think, more compliant with harder regimes. But to start off with something that's more than twice daily or has dietary restrictions, I think, is really asking for trouble. So, it's tailored already in that way and I'm not a draconian in my descriptions of time, like if you're two or three hours early or late, don't worry about that, you know. You've just got to take them twice a day and get them into you. Sure the ddI is a difficulty, but you know, we talk about how they're going to get around that and when do they have their shower and will it fit in if they wake up, take their pills, then have a shower, and then take the other ones.

Different technical solutions to the problem of adherence can be seen to generate different forms of interaction, which in turn might be thought to generate different capacities in the relevant parties. Here 'simpler regimes' tends to feature as an alternative to the technique of '*building them up constitutionally*' (p.20). The chief value in the latter, we would argue, is *not* the production of compliant 'gym queens', but the enlistment of the patient in a process of thinking about and acting upon the conditions that produce a certain set of embodied routines in their immediate and broader world. We do not wish to bemoan the arrival of slick new products that may simplify dosing, rather we are suggesting that there is something to be learnt from the slight differences in the ways these various technical frames render the patient's world and the participants' relation to them.

difficult to take the number of pills required (Prestage et al. 2001). Similarly, in cultural terms, the affective response to HAART is typically leveled at the number of pills imposed.

Specifically, the various solutions discussed here have the effect of situating the authority to solve the problem that the patient's world is supposed to represent in particular ways. The typical location of this authority in the hands of the doctor detracts from the sense that the patient might also be authorized and enabled to act upon their world. That is, these solutions tend to represent the authority and expertise to 'repair' the problem as properly and purely medical. This may preclude other forms of response in which the patient could have a more authoritative role. So, for example, while we concur with the idea that the social disadvantage faced by gay men may result in an affective state that could be understood as depression, there is a sense in which this understanding *contains* the transformations that such a patient might be encouraged to perform upon their world in response to their situation. We use the phrase 'their world' to refer not simply to their own life, self, and practices, but to the broader social conditions that constitute this life as it is lived. Perhaps the challenge of adherence for doctors is not in assessing (or mending) the stability of individual patients, so much as equipping the patient with the resources to query and transform the patterns of a world that obstruct the task of caring for one's self. What is suggested here is that the feeling of agency that accompanies the work of acting upon and transforming one's world, and authoring one's life, is of the same species as that which enables adherence. Certainly, both can be grounded in a critical and reflective relation to the habituated body.

In this respect, the nature of some of the solutions we have discussed here may bear on a much larger question: the political engagement of communities affected by HIV/AIDS.

To return to more concrete issues, the accounts of PLWHA collected for this study suggest that there is some utility in encouraging patients to think about and act upon daily habits as they bear on treatment, the 'simplicity' of the regime notwithstanding. The capacity to constitute these as an object of reflection may be precisely the sort of skill needed to negotiate the complexities of HAART in the context of always changing patterns of living. However, despite the existence of standard techniques at the outset of therapy that could have this effect, there were only a few expressions in these accounts of the need for ongoing efforts to develop something like a patient expertise on living with treatments. 'In/stability' was more usually addressed as an aspect of 'being' (personality), one that might or might not be repaired through specific medical solutions. It is conceivable that this approach may, in some instances, have the effect of rendering the skills needed for achieving well-being as forever beyond the grasp of the individual, who is positioned as capable only of reaction, and not action.

NEGOTIATING QUALITY OF LIFE

So far, it would be possible for readers of this report to take the more detailed engagement with the patients' world that it depicts as an argument in favour of more thorough efforts to improve compliance. While this is the case, in so far as efforts to develop the sort of patient expertise we have described are highly likely to benefit adherence, we have distinguished

28 We are grateful to Marsha Rosengarten for pointing out the example of Trizivir.

such efforts from those that construe the patient's world as an 'impediment to the solution', i.e. something that must be aligned with medicine for the purposes of compliance. This is because, as we hope to illustrate in this section, a patient expertise around living with treatments may produce more possibilities than that envisioned by simple compliance.

We have understood 'expertise' on living with treatments as the capacity to make considered evaluations of treatments and the patient's world and how each bears on the other. This requires opportunities to reflect on how identity, lifestyle, experience and values bear on treatments (and treatments on them), and not simply the provision of medical knowledge. Indeed, it entails a critical perspective on the value accorded medical knowledge in relation to knowledge of the patient's world. Developing this expertise involves co-constructing an understanding of the material constraints of a patient's situation in such a way that the patient can meaningfully evaluate and act upon these in their own terms. In this sense, the task is more intensive than the 'consumer' model of practice, but less directive than the 'traditional' model. In HAART exchanges, the topic of 'quality of life' provides some examples of the ways in which practitioners are endeavouring to strike this balance.

In the previous section, the concept of a 'technical frame' was introduced as a way of thinking about how, as 'problems' and 'solutions' take shape, different forms of expertise are anticipated, involved, and authorised. According to recent research:

Each social group involved in the development of a technological process will thereby seek to mobilise its forces and allies so as to propagate its variant of both the problem and the solution. The contests between such groups will proceed until a position of 'closure' is arrived at. The latter depends, of course, on a general agreement among all contesting parties that the real problem has been identified and, finally, solved.²⁹

Since the advent of HAART, the technical framing of the problem of living with HIV/AIDS has undergone significant change, with the perspective of PLWHA achieving varying degrees of legitimacy. In the enthusiasm of early intervention, there developed in some spaces a strong moral stance in which PLWHA refusal of therapy was portrayed as illegitimate.³⁰ Since then, elements of the patient's world and the lived effects of treatment have acquired some recognition and authority within medical discourse, and led to substantial changes in when, what, and how therapy is prescribed. In the words of Bruce, a high caseload practitioner in the inner city with predominantly gay male patients:

*IS YOUR IDEA ABOUT THE LIKELIHOOD OF PATIENT ADHERENCE A
FACTOR IN YOUR DECISION TO PRESCRIBE?*

²⁹ Banks and Prior 2001:20.

³⁰ See the discussion in Race 2001a; 2001b.

Definitely. I mean definitely now because your fingers get burnt or got burnt or mine did very early on with all the sort of rosy flush of proteases and —

WHEN YOU SAY YOUR FINGERS GOT BURNT WHAT DO YOU MEAN?

Um well you put people on these - I think initially we thought that people were just going to be so glad to get on the treatment they were just going to stay on it no matter what and so you were quite happy to put people on treatments and then in retrospect, you know, you would have spent a lot longer working out whether they were going to take those treatments and —

The issue extends further than the virological outcomes afforded by good adherence, however. The debates, since 1996, around quality of life, early intervention, side effects (especially lipodystrophy), and treatment interruption indicate that HAART is an ongoing site of negotiation. The lack of 'closure' on these issues suggests a lack of 'general agreement among all contesting parties that the real problem has been identified and, finally, solved'.³¹

In this time, 'quality of life' has emerged as an abstract usable concept by means of which PLWHA (and those who advocate for them) have forced some recognition of the limitations of available therapeutic regimes and their objectives, the effects of which are deeply felt. Since 'quality of life' is widely recognized as a legitimate objective of general or holistic clinical care, General practice can be identified as a key interface in which negotiations over quality of life take place. Recently 'quality of life' has framed discussions of the intolerable effects of treatment ('side effects') as well as the difficulties of managing demanding pill regimes over the long term ('pill burden', 'treatment fatigue'), and broader concerns - emotional, financial, spiritual etc. Attempts to objectively determine quality of life, though sometimes playing an important strategic role,³² have been shown to always impose an external value system - a particular view of what is important in life - on individuals and cultures.³³ Thus the usefulness of the term - at least in this context - resides in the *impossibility* of determining a life's quality without reference to the patient's personal evaluation of their circumstances. Because it is 'complex, subjective, and dynamic',³⁴ quality of life always exceeds attempts to quantify it. It has arisen as a theme when the worth of a medical solution is in dispute. For PLWHA in recent years, quality of life has cleared a space in which a critique of HAART (in terms of the broader circumstances of life) can be made and entertained. When invoked, it attempts to confer patients with a legitimate voice in (or some control over) the construction of problems and solutions.

It should be acknowledged that these tactics have been the province of a fairly sophisticated negotiation of the clinic, and presume a particular cultural literacy. Indeed,

³¹ Indeed, the private nature of many of these negotiations (between individual doctors and patients, and in the context of each individual patient's life), and the fact that people's lives change, suggest that such 'closure' is unattainable. This draws attention to the need to attend to the issue of patient expertise when considering such negotiations, and when developing educational initiatives that address this site.

³² For example, in arguing for basic standards of care in resource-poor areas.

³³ See Jones et al. for a good overview of recent critiques of quality of life.

³⁴ Jones et al.

one of the anomalies within quality of life research is that 'better off' individuals tend to assess their satisfaction against higher standards, while those who are less well off have lower expectations. This is not unlike the issue encountered earlier regarding choice: for all the talk of 'options' and 'choice' surrounding HAART, comparatively little attention has been turned to how PLWHA can be assisted to constitute their own world so that it presents real choice. The potential for 'quality of life' to resist the value accorded medical knowledge at the scene of General practice, so that an evaluation of living with treatment can emerge in the patient's terms, means that it could well serve as a useful device for wedging the patient's world further into the exchange. That is, it may be a means of strengthening this cultural literacy in a broader population.³⁵

In this regard, it is worth mentioning that a critical perspective on the effects of medical authority is quite crucial to the business of generalist clinical care, also, at this point in the epidemic. As Clive related:

...occasionally you get a shock because people have just not told you about a side effect they've had for a long time. I guess and you think you've probably not - uh allowed them to tell you, there's probably a bit of a failing. Say someone has had diarrhoea for months and they haven't mentioned it to you, they've just assumed that oh that's part and parcel of it. Um so anyway I guess, yes, sometimes when a person's been coming in for a while it's easy to glaze over those things...

Apart from the clinical application intimated above, it appears that a key challenge for GPs is to try to strike a balance between giving medical advice and keeping the patient engaged. There was a level of awareness among doctors that patients who could not reconcile given medical advice with their own lives would not come back. Attempts to grapple with this problem might be conceived as adopting a variety of harm reduction logic. Techniques such as advising patients to stop therapy if they were sporadically missing doses, and treatment breaks to counter 'treatment fatigue', were reported.³⁶ Typically, the divergence between patient values and medical advice was portrayed as 'of greater consequence' (and requiring more directive approaches) when health deteriorated below 200 T-cells. These techniques try to accommodate the broader dimensions of life/health, but were often also justified in terms of clinical outcomes. Many of them might be enhanced by a more thorough understanding of how to continue to involve the patient in the face of the potential for medical authority to be experienced as imposed.

Some insight into the effects of current configurations of medical authority can be gleaned from the following account. It is difficult to collect accounts that critically reflect on the doctor-patient relationship from PLWHA participants in face-to-face social research,

³⁵ On the other hand, the current use of the phrase 'living well' in place of 'quality of life' in some PLWHA circles may be a response to how the phrase 'quality of life' gets colonised by medicine.

³⁶ A small number of doctors objected to the extension of the notion Structured Treatment Interruption (a term which they saw as referring strictly to the impact of treatment breaks on viral activity and immune function) to treatment breaks made on the basis of 'treatment fatigue'.

in part due to the personal investment in choice of doctor.³⁷ However, Greg, a participant in the HIV Health in Context study, offered a description of some of the challenges of registering his experience of side effects. He is a gay man who works fulltime in inner city Sydney, aged 40, and in general his account suggests that he is highly/unusually adept at negotiating the clinical field. He explains:

Well side effects are part of that general pool of knowledge as well. Um in that when you start a drug you want to know what potential things are going to happen and when you're on a drug you want to compare with what's happening to you, but the reality versus what you read or are told is totally different. Um I mean Saquinavir is appalling for diarrhoea, and one of my friends told me that he was on Saquinavir and he said, you know, 'I thought I was going to fart and I actually had diarrhoea and like soiled everything and it was a really embarrassing experience' and I just sort of thought 'oh ha ha it can't be that bad'. Well it's happened to me once and I know it's that bad. It is the most humiliating and embarrassing experience you could ever want and although I've been warned it wasn't the same thing as experiencing it.

And its like the cramps I'm talking about with the current drugs. I can't describe them to my doctor. They are so uncomfortable and intense but I cannot for the life of me make my doctor see the gravity and significance of the side effect. And it has to be a side effect because it's immediately after taking the bloody pills. So, if I can't describe it I'm wondering how you could write it to say this is a side effect you can experience. I mean I call it a cramp, but that doesn't give it the credence I want to give it, it's – I just want to curl up in a ball and hug myself until it goes away. It's like really – even saying that doesn't sound – I mean when it happens it's like it's awful.

Later he discussed his experience with lipodystrophy:

The clinical description of the side effect versus the reality. It's like – I'm sure it's probably head stuff – but like one of my big things this week and it may sound silly is um – I feel silly saying it – I looked in the mirror some mornings this week and I thought I look like a monkey. Because I'm getting these really classic lines here which are lipodystrophy lines, you know, and I don't like them. And my doctor says, 'what are you worrying about you vain queen'. But I really – this week particularly it's been really worrying me. I really hate it. And to just write on the, you know, on the fact sheet, you know, lipodystrophy may be experienced or whatever –

YEAH, DOESN'T CAPTURE THOSE –

Doesn't capture the reality for me.

³⁷ Indeed, such investment may well stall the sorts of reflection that bear on adherence, and good clinical outcomes more generally.

This passage conveys something of the challenge that individual patients have faced in negotiating for quality of life. It also points to one of the weaknesses of how the world of the patient is apprehended in compliance discourse. The inclination within this discourse to construct this situation as an utter impediment to care invokes the disqualification of the patient's perspective as a legitimate response. (Here, this has been achieved by a quipping on other aspects of the patient's dubious status ('*you vain queer!*'). This in turn eliminates any ground upon which the doctor and the patient can engage together in the process of constructing solutions to these material circumstances, save the insistent imposition of medical dictates and/or bracketing of the patient's experience. This could further contribute to a sense of a lack of control on the patient's part, detrimental to adherence. That the eventual solution might call into question some of the values with which the patient currently apprehends his world is by the by, for in this move the patient has been altogether excluded from the negotiation.³⁸ With great efficiency, his world has been excised from mutual or thoughtful consideration.

Perhaps the above analysis does not allow for the possibility of an affectionate tone to the doctor's comment, and underestimates dry humour as a productive mode of engagement between doctors and patients in HIV/AIDS, (though it seems to have missed the mark in this instance). The important point, however, is that the frame of compliance hampers a more intensive consideration of the sense the patient is making of the situation, stopping short further expansion of the matter.

In practitioner accounts of lipodystrophy, two contrasting approaches can be identified that largely parallel the different models of practice we have discussed. In the first (also illustrated above), treatment morbidity appears as an obstacle to care, one whose credibility is subject to doubt:

DO YOU THINK THAT THE LIPO STUFF - LIKE THOSE MANY ISSUES ARE A LEGITIMATE SORT OF CONCERN OR —

I do, yeah. I mean because if you're - it's so difficult though. I mean it's sort of like if your choice is cosmetic versus death, you know, that's kind of pretty easy to go well, yeah, here take these. But that's where the waters are very muddy now. Because people who have been so well for a long time on their protease inhibitors and they feel fan - you know they feel relatively well, but then, you know, the only thing they see that HIV does to them is the drugs. So, yeah. It's hard. I mean yeah of course I try and, you know, I do use a lot of protease inhibitors, but yeah, —

IT'S DIFFICULT.

It is difficult.

³⁸ Alternatively, the part of the patient's world that could be subject to question might be current pharmaceutical practices.

The contrasting approach, which tended to be adopted by gay male doctors, was content to leave certain elements of the patients' world to stand:

I think lifestyle is a very very important thing. That's for gay men. Their physicality. You alter their physicality they'll never forgive you, hey. [laugh] You know, honestly and, you know, it's about self-esteem. Your pulling power is where your self-esteem is based. I think good self-esteem always allows people to go on with treatment from the ones that don't care.

If the description of the available choices as '*cosmetic vs. death*' does away with the gravity with which the condition is experienced by some patients, thereby dismissing the authority of the patient's account of their experience, gay doctors' identification with their patients invites a different stance. This tended to be one that safeguarded the assumed values of the patient's world. Philip said:

I'm very in the patients world and what amazes me, has amazed me since lipodystrophy has been around is the number of patients that I haven't seen for years or are new to me who've come saying, I don't know if this is perceived because I'm perceived as being a gym queen myself. [laugh] They want to see firstly a bloke and they want to see a guy who will understand their concerns about body image and, you know, what it's like to be a queen who has lost his tits or something like that. Or I want my bum back.

Yeah, and many come in saying I want my bum back, you know, can you do anything. Give me an answer and, you know, and I - you know, I understand, I suppose. Or they perceive that I understand. So, I think for a long time, always - right through this illness my thing has not been about prolonging life over quality, I think. Some people say that's what they want. I think that's a rare bird. Most people want to have a happy life for as long as they happen to live and sure we want that to be as long as possible. But in my own social circle maybe this is the vanity of the queens I hang around with, who want to die beautiful, you know, and there's no doubt about it, you know, they will say to me, particularly if they're used to being perceived as cute, that if they had to walk around looking extremely lipodystrophic they wouldn't go outside their front door. Now, that might be perceived by some as the shallowness of their gay priorities, but that's not for me to judge ... So, I don't make the priorities for the patients, they've got their own.

This creates an important contrast to the light in which lipodystrophy appears under strict compliance. What emerges is a critical perspective on the value accorded medical knowledge. As this doctor recognizes, medical mandates are not free of value judgments about what is important in life. Further, the power relation is such that one set of 'priorities' may potentially be imposed on the other. Here 'quality of life' has elicited a consideration

of how the different moral frameworks and the power relation implicit in the positions of doctor and patient are negotiated.

This identification and sympathy with the patient's world is admirable, and can be considered an important vector that has modified practice. One is nevertheless left with the impression from these accounts that that which is taken to constitute 'quality of life' or 'self-esteem' is presumed, rather than explored. Since, as we have discussed, the values of the patient's world tend to feature as ancillary to practice, rather than being explicitly invoked in the clinical exchange, this is not unexpected. However it leaves practitioners with slim resources to respond to situations in which lipodystrophy, for example, has occurred. A certain impasse and resignation is the result. For example, in the context of a discussion about whether long-term effects influenced decisions about whether to keep people on treatment, one high caseload doctor said:

Oh yeah, I mean, you know, yeah, it does. I think but lots of other factors do too. Just one of many and it's for the individual, you know, I just don't – I don't have a fixed formula and I'm also willing to accept anything new and, you know, I'll quite openly say that if I threw you on a protease inhibitor four years ago I'm sorry. I mean maybe I shouldn't have at the time, I should have waited. If they've become lipodystrophic, you know. I don't have all the answers. I don't pretend to. I just want to keep you well for the longest period of time.

Generally, what was not forthcoming were ways of enabling the patient to explore their situation in affirmative terms.

If there are dangers in the way that 'compliance' erases the legitimacy of patient concerns, there is also a danger that the presumption of sameness between doctor and patient (found in these examples) could erase certain differences that might otherwise be a productive basis from which to explore or problematise the conditions that make up the patient's – or indeed the doctor's – world. Rather than take this world as given, and proceed from the presumption of a sameness between doctor and patient, an alternative would be the invention of deliberate strategies designed to evoke and explore what the patient singularly deems important. In this process, the power of medicine to impose one set of priorities on another would remain a key propensity to guard against.

Bruce offered a suggestive tale that might venture preliminary resources for transforming some of the real affects of this situation. After describing the difficult position HAART puts him in, as a doctor who is also a member of the gay community, he mentions an event that suggests tentative ways of querying the self-evidence of some of the meanings surrounding the condition:

Yeah it's certainly something that's got to be - it's kind of talked about as lipodystrophy, but the fact we're not really talking about - we're making people visibly recognisable at the moment, I think, you know, I mean often being in the community you often realise that and you suddenly, you know, when you're noticing

all your friends get sort of lipodystrophy. In fact what you're doing when you are prescribing these drugs is - I mean you're certainly giving these people benefit but you're actually doing something like that, that you've got to broach with them I think, in the end. So, it's kind of - it's a point, I suppose, now, where we're getting more into it, that we'll have to deal with it...

I suppose the interesting thing was one person who was just absolutely paranoid about lipodystrophy, in fact two men who were paranoid about it, you know, tried to pick each other up a waiting room because they both thought they looked pretty hot and it was sort of just the absolutely cut body and the sort of slightly prominent cheek bones and it's kind of like - it was very funny neither of them thought that the other had lipodystrophy at that point, which is kind of interesting.

This tale experiments with the possibility of querying how (sexual) value is produced in the patient's world, a world in which this doctor also positions himself. While it would clearly be inappropriate for medical practitioners to insist on these alternative ways of making sense of the condition, this instance alludes to the sort of mutual and delicate engagement that might be pursued with patients in relation to their worlds. What such an engagement would require is the permission and support for the patient to embark on a process of evaluating the values of their world.³⁹ Handled sensitively, such a process has a chance of expanding the qualitative dimensions of their experience, creating new possibilities for thought, feeling, and action.

In this respect, we take seriously, if cautiously, the suggestion that for some people, the event of HIV has been an opportunity for 'a major reassessment of values' that has 'often been strangely but profoundly life-affirming'.⁴⁰ One doctor referred to the opportunity to engage with some patients' engagement with their own values as enriching his own experience of doctoring, and of life. Might general practice be thought and practised in ways that are conducive to such a process?

CONCLUSION

The production of patient commitment to therapy is a question of how the patient is authorised to participate in the solutions that take shape. This is a matter of how the patient is addressed by medicine. Against questions of morals ('you must' or 'you must not') can be set questions of ethics, in which participants ask the question 'Who am I to say to the other 'you must' or 'you must not' and how will this statement define my relation to this other?' Here, ethics is

³⁹ Here we note that appearance is not the only negative material effect of lipodystrophy. Also, while the production of sexual value is one domain that might be challenged, the present practices of the pharmaceutical industry are quite clearly another pertinent component of the patient's world that might be subject to transformation.

⁴⁰ O'Donnell, M. 2001.

...judged less by the types of solutions that are proposed for problems than by the way in which the positioning of the problem and the solutions proposed situate and involve those to whom they are addressed.⁴¹

If patient autonomy is both an important element of adherence, and important to consider in questions of quality of life, what may be useful about this formulation is the way it places questions of patient autonomy firmly in the context of specific practices of relating between doctor and patient. In 'quality of life' discourse, what seems to (or might potentially) emerge is ethical thought on the ways in which patient autonomy implicates certain practices of relating. Here, autonomy is not so much a pre-given attribute of patients, but something that is - at least in part - continuously forged, constrained, and enabled through these practices in the clinic.

The key question that emerges is how particular solutions involve patients in - or exclude them and their experience from - their own care.

The models of adherence that currently govern practice seem to envision the patient's world (and the experiences, values, and practices therein) as something to be fixed by medicine, or else not proper to the business of General practice. A differing version of care might regard this world as a substance upon which the patient might work, with the help of others. In this report, we have proposed that the feelings and capacities that such work produces might better equip patients to take medicine into their lives.

⁴¹41 Stengers 1997: 222.

Compliance Supportive Communication

Understanding interactive sequence and knowledge/power relations in HIV treatment negotiations

David McInnes Kane Race, Veronica Kleinert, Marilyn McMurchie, Michael Kidd

INTRODUCTION

This paper develops an analysis of doctor patient communication patterns in HIV treatment clinical negotiations, primarily interactions related to the uptake of or changes to treatment regimes to assess their effectiveness in supporting patient compliance. The study reported on here was a pilot study which sought to add some specific detail to knowledge about the ways in which interactions between patients and doctors might assist, inform and support patient compliance. In this sense, the study and its findings are intended as suggestive, rather than representative and conclusive.

Framed by other discussions of medical communication (Moore et al., 2001; Silverman 1987; Mishler, 1984, 1997; Wodak, 1997; Tannen and Wallat, 1993; Makoul, 1998), our analysis focused on six tape-recorded interactions between doctors and patients in HIV clinical encounters. The interactions were about treatments, either uptake or discussion of regime changes, and the experience and impact of treatments.

The analyses deployed were both macro discursive analyses and micro linguistic analyses. In this way, both a post-structuralist informed critique (Foucault 1966, 1972) and systemic linguistic analysis (Halliday, 1978, 1994; Martin 1992; Ventola, 1987; Eggins and Slade, 1997) were combined into what is described as a Critical Discourse Analysis (Fairclough, 1992). The aims of the analysis were to describe interactive linguistic patterns and to give some account of these (their constraint and typical patterning) in relation to power and knowledge formations. Doctor and patient interactive linguistic behaviour was seen as configured as part of and determined by (and determining of) larger discursive formations and more immediate contextual constraints.

ANALYSIS

In approaching the analysis of our limited data set, we were struck most by two things. One was the way in which doctors took up knowledge producing or clarifying roles in interaction most of the time and two was the way in which patients were provided their turns at talk by the doctor's interactive turns.

In an earlier paper, Race et al. suggest that "the clinic is not simply a site for medical problem-solving, but may also be an opportunity for developing a literacy around dosing as a social, context-mediated act." They explain that in their analysis they

Used texts on the clinical encounter as a window into the discursive formations that govern doctor-patient relations. This discourse limits and creates enunciative potentials in the encounter between doctor and patient, governing how patients do 'patienting' and doctors do 'doctoring'. It is this discourse to which the tools of critical analysis might usefully be applied in order to rethink the ways in which adherence is promoted. [Emphasis added]

It is an exploration of the enunciative potential of the clinical encounter that propels the current project.

Our assumption is that in deploying this enunciative potential, communication in the clinic and surrounding the clinic should be of a kind that enables a knowledge producing collaboration between doctors and patients. The knowledge that we are focused on here is that which frames understandings of treatments and a patient's compliance. This knowledge should emerge from equal contributions of doctors and patients, both in terms of turn taking/amount of talk, and in terms of contribution to knowledge as constructed in relation to both medical/clinical knowledge regarding treatment and knowledge pertaining to the 'life' experience of the patient (lifeworld knowledge).

Collaboration is produced, we argue, when each contributes to a jointly constructed understanding or knowledge of these things in relation to one another and with a critical perspective on the value accorded knowledges. This means that at a generic level, the problem^solution model of consultation may need, at times, to give way to interactions that are more process oriented and facilitative of patient and doctor co-constructing the knowledge of a patient's life. In this new knowledge domain, HAART might be understood or made known as one part of a more complex life picture.

We will also suggest in this paper that the explicit reframing of interaction to produce such collaborative knowledge is one way to resist what is, for both patient and doctor, the dominant knowledge formations of medicine and science, knowledge formations which preclude a more compliance supportive communication.

The doctor and patient in the following sequence are discussing the way in which a 'simple' regime of drugs is ineffective in part because of a patient's non-compliance. It

therefore represents a key kind of negotiation in terms of our project's focus – the way in which interactive communication might or might not support compliance. This interaction between doctor and patient is an interesting place to start our discussion.

In all of the interactions reproduced here the doctor's moves are in caps and the patient's are in lower case.

Interaction One

- 1 *It's something I haven't really sort of come across yet. I haven't had to swap over the treatment I first started.*
- 2 *IT'S BEEN QUITE STRAIGHT FORWARD, HASN'T IT?*
- 3 *Yeah, yeah.*
- 4 *JUST TWO PILLS TWICE A DAY.*
- 5 *It's simple. Simple combination, yeah.*
- 6 *I GUESS THE PROBLEM HAS BEEN THAT UNFORTUNATELY THE RESULTS HAVEN'T BEEN QUITE AS GOOD AS WE'D LIKE. I SHOWED YOU A GRAPH DIDN'T I?*
- 7 *That's probably because of my not complying I suppose. Yeah, it is.*
- 8 *YOU MISS THE ODD TABLET DON'T YOU?*
- 9 *Very occasionally. Sometimes more than occasionally.*
- 10 *ABOUT HOW MANY TIMES A WEEK ARE YOU MISSING?*
- 11 *Sometimes – I always have at least one dose a day, but sometimes I might do that – like in the three days or four days, but not every week.*
- 12 *SO, TWO OF YOUR TIMES A WEEK YOU JUST HAVE THE PILLS SAY IN THE BREAKFAST?*
- 13 *Yeah. I usually always have breakfast, but I miss tea occasionally.*
- 14 *AND WHAT HAPPENS AT TEA DOSE?*
- 15 *Um I'm not home or I'm tired and I go to sleep and I forget or I just forget.*
- 16 *AND YOU JUST SAW THE TRIAL NURSE HERE DIDN'T YOU?*
- 17 *Yeah.*
- 18 *ABOUT HAVING SOME BLOODS TAKEN?*
- 19 *Yeah.*
- 20 *DID SHE TAKE SOME BLOODS?*
- 21 *Yeah, she did, yeah.*
- 22 *OH GOOD. YEAH, SHE EXPLAINED ABOUT THE STUDY DIDN'T SHE?*
- 23 *Yeah, she said it was to see which antivirals worked best on my blood samples before I actually tried to take a new course.*
- 24 *I GUESS WHAT WE'RE LOOKING AT IS TO SEE IF SOME RESISTANCE IS HAPPENING.*
- 25 *Yeah.*

- 26 *BECAUSE YOU'VE BEEN ON THESE TABLETS FOR –*
- 27 *A couple of years I think?*
- 28 *YEAH, I'LL JUST CHECK AND SEE. IT'S A WHILE. ACTUALLY, YEAH, ACTUALLY A LONG TIME. THREE AND A HALF YEARS.*
- 29 *Oh it's been a while, yeah.*
- 30 *I MEAN THEY'VE REALLY WORKED VERY WELL MOST OF THE TIME. IT'S ONLY JUST RECENTLY YOU'VE BEEN HAVING MORE TROUBLE, BUT INTERESTINGLY YOUR T-CELLS HAVE ACTUALLY DONE VERY WELL ON THIS TREATMENT EVEN THOUGH THE VIRUS IS DETECTABLE UM THE VIRUS JUST ABOUT GOES BACK TO NOTHING I THINK WHEN YOU TAKE THE TABLETS A HUNDRED PER CENT DOESN'T IT?*
- 31 *Yeah. When I take them a hundred per cent, yeah it works well. It goes down to zero, but I'll have to do something about that somewhere along the line. Yes, I've got a new mobile and it's got a – what is it? A wake-up call so I can use that to remind me to take my pills.*

What is of principle interest in this interaction is its interactive structure and the roles given to and taken up by the two participants. The sequence of negotiations, that is what is to be talked about and in what order, is determined by the doctor's moves in the exchange. In all of the doctor's moves (in caps) the topic and the perspective taken on the topic are chosen by the doctor. This forms an interesting pattern against the way the doctor puts the patient in the role of (interactive) 'knower', that is the one in the exchange who 'knows' the information sought by questions. Most of this placement of the patient as knower occurs through tagged declaratives (2, 6, 8, 16, 18, 22, 30), or through intonation which indicates the patient should confirm or negate the moves by the doctor, or by direct use of interrogative (question) structures (10, 14, 20). This is not a knowledge-producing role for the patient in that he is positioned to confirm rather than elaborate knowledge, but a knowledge producing role for the doctor.

The doctor takes the role of stating, declaring and explaining the facts of the patient's regime and its success (6,30), the patient's compliance (8, 10, 12, 14) and the patient's experience in the clinic (18, 20, 24).

The doctor places the patient in this role in all but 3 moves (26, 27, 28). However, at this point a 'fact' is clarified by the doctor after the patient 'gets it wrong' (27), and then is returned to the role of confirming the doctor's declaration in move 29.

Move 7 is the only contradiction to this pattern and is marked most acutely by the way in which the doctor does not take up the patient's constructing of this topic – compliance is replaced as a verb by "miss" and the following moves unfold via the doctor's questioning. Interestingly, at 13 the patient's reference to 'tea' is picked up by the doctor in his question at 14, but the information offered at 15 by the patient is left without exploration.

The doctor is not 'rail-roading' the patient, but several elements of interactive linguistic behaviour prevent the detailed elaboration of the patient's experience both of treatments and their impact and, more extensively, his lifeworld. These patterns *foreclose* elaborated discussion.

In the next interaction, there is more of a contribution to the knowledge being produced by the patient, but it is still possible to see how the interactive sequence and roles foreclose an elaborated and collaborative discussion of the breadth of factors that may impact on the patient's compliance.

Interaction Two

- 1 *AND THEY'RE ALL OKAY WITH YOU?*
- 2 *Yeah, well a bit suss on the Nevirapine, but ---*
- 3 *THAT'S RIGHT, YEP. AT THE TIME WHAT HAPPENED WHEN YOU HAD NEVIRAPINE?*
- 4 *Just hyper – hyperactiveness – like hypersensitivity or whatever it's called. A bit aggressive, agitated.*
- 5 *BUT WHAT ELSE WAS HAPPENING THERE?*
- 6 *Oh well I was having a few problems and I was also put on steroids for my skin. So, I read that they react to each other. I shouldn't have been put on them?*
- 7 *THAT'S RIGHT. I MEAN IT HAS COME UP MORE RECENTLY THAT UM STEROIDS AND NEVIRAPINE DON'T GO VERY WELL TOGETHER. IN FACT WHEN I WAS AT THE HIV CONFERENCE SOMEONE PRESENTED A PAPER ABOUT THAT – THAT PROBLEM THAT YOU GET WITH THOSE TWO THINGS. SO, THIS TIME, I MEAN, THERE'S NO NEED FOR STEROIDS, SO -*
- 8 *No.*
- 9 *YOU SHOULD GO THROUGH THAT QUITE WELL. BECAUSE THAT REACTION IS FAIRLY UNCOMMON WITH NEVIRAPINE, BUT COMMON WITH STEROIDS.*
- 10 *Right.*
- 11 *SO, I THINK IT WAS PROBABLY MORE FROM THE STEROIDS.*
- 12 *Right.*
- 13 *HOW LONG DID YOU ACTUALLY HAVE NEVIRAPINE THAT TIME?*
- 14 *I actually had it for a while and it was – I think I'd had it for about six months and it really got my t-cells – my viral load down and t-cells up. So, it worked. It was just when I had that reaction I sort of stopped.*
- 15 *RIGHT. OKAY, WELL YOU SHOULD BE ALL RIGHT THIS TIME.*
- 16 *All right.*
- 17 *I MEAN ALL OF THESE TABLETS YOU'VE HAD I MEAN YOU KNOW WITH NELFINAVIR YOU GET A BIT OF DIARRHOEA.*
- 18 *Yep.*
- 19 *D4T YOU GET TINGLING AND NUMBNESS.*
- 20 *Yeah, mainly in winter I feel it, but ---*
- 21 *3TC IS PRETTY SAFE.*
- 22 *Yeah.*
- 23 *AND NEVIRAPINE CAN CAUSE A SKIN RASH. WELL I'VE SEEN YOU WITH THAT. BUT THAT DIDN'T HAPPEN LAST TIME?*

- 24 *Didn't happen, no.*
- 25 *OKAY, WELL IN THAT CASE YOU SHOULD BE RIGHT THIS TIME WITH IT. AND THAT TIME – WHY DID YOU HAVE THE STEROIDS THAT TIME?*
- 26 *For this – and I ended up like going to see a specialist and he told me to stop using everything that they were putting on and it went away by itself. I mean it's very occasionally ---*
- 27 *THAT'S THE SEBORRHEIC DERMATITIS.*
- 28 *Seborrheic dermatitis, yeah, sorry.*

In this interaction, the doctor still determines the sequence of the interaction, in that he choose topics and moves the conversation on to new topics.

In this extract, there are 3 points where this pattern is potentially disrupted. At 4, 6 and 14 the patient is taking up a role of expanding discussion of his experience of the drug regime he was on and the reason, at 14, for stopping.

At 4, the patient opens a discussion of side effects. At 5, rather than explore this or ask the patient to provide him with an expanded account of the impact of the drugs, the doctor actually directs the conversation elsewhere, and then after the patient's response at 6, draws in recent medical knowledge, 'translating' for the patient, and concluding with a declaration that 'this time there is no need for steroids', ending the topic. The patient is in a position simply to agree by confirming with 'no'.

Again, at 13 the doctor asks the patient for an account of the length of time that he took Nevirapine. In response, the patient tells the doctor how long – six months – but then accounts for why he stopped, 'It was just when I had that reaction, I sort of stopped'. In that the patient begins an expansion of his experience around the drugs and their impact on his life and decision making, there is an opportunity for an extended turn at talk on the patient's part, perhaps facilitated by questions and prompts from the doctor. Instead, the process of assessing which drugs were 'ok' for the patient's use continues through moves 17 – 25 with the doctor organising not only the topics – which drugs and their impact, but assessing and evaluating the impact of the drugs for the patient in terms of side effects.

Two moves, 20 and 26, also see the patient provide lifeworld information regarding the impact and negotiation of drugs in his life but in 21 the doctor moves the conversation along without taking an opportunity to discuss the issue of numbness as it is beginning to be constructed by the patient. At 21, the list of drugs is continued so that the doctor can assess which work and which do not – the list, in this sense, is a meta-script determined by medical/pharmaceutical technology and its determination of assessment as facilitated by the progress of interaction.

At 26, the patient gives an account of side effects and his relationship to the scenes of medical discourse and management that he is subject to. Rather than explore this, the doctor provides the correct name for the side effect that the patient experiences. Interestingly, in response to this 'corrective' the patient uses the correct term and apologises for getting it wrong.

We can see very clearly here the way in which two kinds of knowledge are brought together in the clinical encounter. One is the medical knowledge of drugs and their impact. This knowledge also propels the process of interaction through a sequenced discussion of the drugs and their impact as they are placed in and determining of the doctor's assessment process. The other knowledge is that of the patient's experiences of his life and of his taking drugs in his life. This second also contains knowledge of the patient's experience of negotiating the medical domain – its voices, and authorities and assessments on prior occasions. These separate, though related knowledges, are the authoritative domains of the two different interactants in the exchange.

Crucial in our considerations is the sense that these two 'knowledges' must be brought together in the clinical counter – there is a necessary interdiscursivity in the negotiation and discussion of treatments between doctor and patient (Moore et al.; Fairclough). From our point of view, what the encounter and its participants need to be aware of and work against is that one of these domains or knowledges is privileged and powerful in the clinic.

This power and value of medicine and science is realised in two patterns that we have so far identified – the interactive sequence of clinical encounters and the roles taken by the different participants. Not one of these things realises or enacts the power of medicine over the discourse of the patient's lifeworld, rather it is the two things in tandem that foreclose the possibility of expanded discussion and exploration of the second less-valued and less-privileged discourse. It is, we contend, only through exploiting or opening-up discussion in the patient's life discourse in connection to and in relation to the discourses of medicine that a more collaborative construction of understandings of treatment, a patient's experience of treatment and compliance can be enhanced.

Prior to an exploration of some interactions which suggest ways in which collaborative knowledge production might be achieved through interactive skills and strategies, we need to make clear what it is we mean by knowledge, how this relates to the different discourses drawn into clinical encounters and how the roles of doctor and patient and the sequence of their exchange produce a valuing of one and its power in the exchange; and a foreclosing of the exploration of the other.

KNOWLEDGE/S

Knowledge, in our analysis, is not information, but is about ways of understanding the world and experience formulated and valued from particular discursive 'viewpoints'. Following Foucault, we would suggest that 't[T]he function proper to knowledge is not seeing or demonstrating; it is interpreting' (1966: 40). Knowledge is generated by 'ways of seeing' and is directly connected to the reality producing capacity of language. It is in this way that languages capacity to formulate and encode 'views' of the world that discursive domains are marked in text.

Knowledge is that which one can speak in a discursive practice...; knowledge is also the space in which the subject may take up a position and speak of the objects with which he deals in his discourse...; knowledge is also the field of coordination and subordination of statements in which concepts appear, and are defined, applied and transformed...; lastly, knowledge is defined by the possibilities of use and appropriation offered by discourse... there is no knowledge without a particular discursive practice; and any discursive practice may be defined by the knowledge that it forms. (Foucault 1972: 182-182)

We have seen already in interaction one and two the way in which the doctor's assessment agenda – that is, the way in which he must explore the impacts and effects of treatments, foreclose the way a patient may be facilitated to discuss and give accounts of the conjunction of treatment and lifeworld experience.

In the section reproduced below from interaction two, we have already seen how medical knowledge is concerned with facts of medicine and science and the appropriate naming of these. Beyond the authority of accurate naming, this piece of interaction also demonstrates the asymmetrical power of doctor and patient in relation to this kind of discourse – the doctor knows and corrects and the patient apologises for the inaccuracy. At one and the same time, the power of medical discourse is about the doctor's authoritative knowledge and the position of knower and authoriser he is given in the exchange.

From interaction two:

- 26 *For this – and I ended up like going to see a specialist and he told me to stop using everything that they were putting on and it went away by itself. I mean it's very occasionally ---*
- 27 *THAT'S THE SEBORRHEIC DERMATITIS.*
- 28 *Seborrheic dermatitis, yeah, sorry.*

In the extract below, we can recall that the patient accounts for the fact, presented by the doctor, that things aren't going well (the doctor has used a graph to represent the clinical facts of this situation). The patient uses the verb *comply*, one located within the medical knowledge domain/discourse. The doctor replies at 8 by not only asking a tagged declarative (the kind of question which requires a yes or no answer) but re-configures the patient's description of his experience with the verb *miss*—medical constructions are replaced by more 'everyday' descriptions.

The doctor's questions, as we have already discussed, then frame, in a set of direct questions, how the patient will discuss the experience of 'missing'. The patient along with the doctor uses non-medical frames for considering 'missing' and the patient refers to missing tea – a use of ellipsis that may be indicative of a 'shared' knowledge between doctor and patient. The doctor then explicitly describes this in his question at 14 as 'tea

dose', a reframing or explicit marking of the way in which the patient's experience is re/named in medical terms.

From interaction one:

- 7 *That's probably because of my not complying I suppose. Yeah, it is.*
8 *YOU MISS THE ODD TABLET DON'T YOU?*
9 *Very occasionally. Sometimes more than occasionally.*
10 *ABOUT HOW MANY TIMES A WEEK ARE YOU MISSING?*
11 *Sometimes – I always have at least one dose a day, but sometimes I might do that – like in the three days or four days, but not every week.*
12 *SO, TWO OF YOUR TIMES A WEEK YOU JUST HAVE THE PILLS SAY IN THE BREAKFAST?*
13 *Yeah. I usually always have breakfast, but I miss tea occasionally.*
14 *AND WHAT HAPPENS AT TEA DOSE?*
15 *Um I'm not home or I'm tired and I go to sleep and I forget or I just forget.*

What we have identified here is the way in which not only kinds of knowledge are deployed in clinical encounters, and valued differently, but the way in which power relations are produced via the configuration and sequencing of moves and interactive roles. Beyond knowledge and who knows it, positions of knowing, configuration and reconfiguration of experiences in medical or lifeworld terms are woven asymmetrically through the exchange.

The clinical encounter is also an encounter between discursive formations, that is between kinds of knowledge and the value accorded them both within the immediate context of the clinic and in the broader culture. The doctor enacts or voices the medical-scientific knowledge and the patient gives voice to their life experience.

The doctor consistently manifests the 'voice' of medicine, the patient's contributions mix the voice of medicine with the voice of 'the lifeworld', or ordinary experience. (Fairclough 1992, drawing on Mishler and Habermas, 143)

The doctor, positioned within a powerful set of knowledges pertaining to medical discourse is not simply a 'voice' which overrides the negotiation and exchange. Medical interviews and encounters are not impermeable scripts and, especially in HIV medicine, encounters are points of discursive interface and, change and reconfiguration.

There may be a variety of encounter styles, developed over periods of the epidemic, in response to various negotiations of domains of power and authority.

“Different varieties of medical interview do not simply coexist: they enter into relations of contestation and struggle, as a part of the more general struggle over the nature of medical practice...In struggles between varieties of medical interview, it is the boundaries within orders of discourse...and the interdiscursive articulation of elements within orders of discourse that are at issue”. (Fairclough 1992: 148) It is the relations between discourses as produced in the knowledge producing or foreclosing process in treatment negotiations on which we are focussed. This issue of medical interviews/encounters as points of interdiscursive articulation and its particular realisation in HIV medicine has been explored by Moore et al. (2001). Following their findings, clinical interactions open-up the opportunity for the two knowledges brought to the clinic to be used to produce new knowledge. Such knowledge production is only possible via a collaboration by those that hold separate and differently valued knowledge. These two knowledges can only be drawn into the same discourse by active, practice-based strategies.

What we are interested in here is less a description of the way interdiscursivity is manifest in the interactions, and more a development of the ways in which particular discourses and joint knowledge production may be foreclosed by interactive linguistic practice. In the concluding section of this paper, we will suggest a number of strategies for dealing with this. For now, it is useful to again reflect on the ways in which different kinds of knowledge are drawn together in the clinic in ways we could describe as non-collaborative.

It is also important to keep in mind that silences are produced, and privileged and powerful knowledge formations dominate if the interactants through which discourses are brought into an interdiscursive relation interact uncritically and unreflectively.

We have seen how knowledge and roles interact to foreclose a broader collaborative understanding of lifeworld in relation to treatments. In the interaction below, in which the doctor and patient do discuss the detail of the patient’s experience in relation to a more holistic approach to health and well being, we see how a medical-scientific framing of lifeworld experience forecloses via a reconfiguration within medical knowledge of mental health and depression.

Interaction Three

- 1 *SO, WOULD YOU – DO YOU THINK THAT WILL BE BETTER THOUGH IN THE END IF HE WENT HIS OWN WAY?*
- 2 *Um probably for me it would be, you know, sort of this last week after he had his turn, I think I’ve done as much as what I can for him now. I mean I’ve given him some life skills and stuff, but it’s just taking up too much of my life.*
- 3 *YEAH.*
- 4 *You know.*
- 5 *‘CAUSE IF YOU’RE NOW REALLY VIRTUALLY A CARER FOR SOMEONE AND IT REALLY MEANS THAT THAT HAS TO BE WHAT YOU WANT TO DO DOESN’T IT?*
- 6 *Yeah, I don’t mind doing it and, you know and if things don’t happen with G. I’m quite happy to do it, but I would like to incorporate a bit more free time for myself.*

- 7 *SOME PEOPLE I MEAN THEY'RE HAPPY TO BE A CARER AND OTHERS IT'S SORT OF FORCED ON THEM AND IN THE END IT REALLY – IT'S NOT REALLY WHAT THEY WANT TO BE DOING.*
- 8 *Yeah.*
- 9 *I DON'T KNOW HOW YOU FEEL ABOUT THAT? BECAUSE IF IT WAS A CHOICE BETWEEN BEING A CARER OR GOING BACK TO WORK WHAT WOULD YOU DO?*
- 10 *Well, in W. case I'd just be a carer. I wouldn't even – I wouldn't sort of have him in a situation where it was – where he was backsliding.*
- 11 *THAT WOULD BE A CHOICE – YOU WOULD BE REASONABLY HAPPY TO DO THAT?*
- 12 *Yeah.*
- 13 *OKAY. IT'S A VERY NICE THING THAT YOU WANT TO LOOK AFTER SOMEONE AND HELP THEM, JUST SO LONG AS THAT'S ALL YOU WANT TO DO THOUGH.*
- 14 *Yeah.*
- 15 *UM AND ALSO THAT IT DOESN'T AFFECT YOUR MENTAL HEALTH. LIKE IF, YOU KNOW, IF IT STARTS UM THAT'S NOT GOOD FOR YOU EITHER. I MEAN YOU'VE HAD YOUR UPS AND DOWNS AS WELL HAVEN'T YOU?*
- 16 *Yeah, well that's why I thought I'll go back to the gym this week and start doing what I was doing, you know, earlier in the year when I felt really good. like the yoga and the gym and stuff. It sort of gives me a little - even like an hour or two out of the house sort of. It just makes me feel like – I meet different people and stuff like that.*
- 17 *AND YOU FEEL HAPPY WHEN YOU GO TO THE GYM?*
- 18 *Yeah.*
- 19 *DO YOU THINK YOU'VE BEEN FEELING A BIT DEPRESSED THOUGH?*
- 20 *I think- no not – I don't think it would be depression. I think it's more the worry. I've been worrying a lot because he's going overseas and stuff like that with his boyfriend and I'm thinking oh ---*

Looking at move 13 and on, what is interesting is the way in which the doctor provides the knowledge domain/frame that is available for discussion and, though the patient is given the role of having knowledge, what is talked about and the parameters of what might be important are provided by the doctor's moves as is the construction of 'mental health' and the proposition of the idea of depression.

FINDINGS

The core finding of our analysis, then, is that foreclosure is produced around certain kinds of experiential knowledge and information producing roles for patients. We would suggest that medico-scientific knowledge dominates both in terms of patterns of exchange, construction of experience and the relative status of elements of experience in relation to drug treatments. This pattern is restrictive of more elaborated discussion of issues that effect compliance.

The linguistic analytical focus of this report has been interactive sequence and interactive role. Our data displayed many more linguistic features and patterns which

pertain to the way in which social relations are constructed between doctors and patients and to the way in which knowledge figures and is valued in interactions. These other patterns and features are also crucial to communication that would support compliance and further research would be of great benefit in terms of description and educative possibilities. For now, and for effectiveness our focus must remain on the two crucial and related foreclosing mechanisms we have identified – interactive sequence and role.

To make alternatives to the communications patterns we have seen clearer, compare the above interactions to the section below from a consultation which is preparing for the commencement of therapies. What we are interested in here is the way in which the turns at talk taken by the patient and the content of these is, to a larger extent than in the previously discussed interactions, under their control. This level of control is clearly connected to the fact that the life/lifestyle, habits and experience of the patient are necessary topics in the discussion of treatment uptake. However, more than simply the elaboration of ‘content’ regarding the patient’s life is important.

Interaction Four (DP6)

- 1 *Well, no I'm happy that one - or as I said my main thing was to delay starting anything until I really have to. Um second thing was that once you have to start um then for me to get the information about overall and then based on - so I understand - and then your recommendation um of what to do. Which is what you're saying. In terms of the trial I don't have problems with trials. My only thing is that if I'm starting off and I know nothing I'm starting from the ground level, I'd rather be dealing with you, which I assume the trial comes through you anyway.*
- 2 *YES.*
- 3 *I'd rather be dealing with one person um that has a plan and we carry on with the plan rather than chopping and changing and coming back and doing more tests to see that it's not working, so let's change this. Because I have - I fear that that will then muck up my foundation for any future stuff. So, that's my only fear with that.*
- 4 *THE FEAR BEING THAT WHAT?*
- 5 *Well, the fear being that we're playing - I'm becoming a guinea pig to play with different combinations which may um and it may not, but it may result in limiting my options in the future um –*
- 6 *YES, I THINK THAT'S A COMPLETELY REASONABLE THING BECAUSE WE WOULDN'T WANT TO DO ANYTHING NOW WHICH WAS SECOND RATE.*
- 7 *Yes.*
- 8 *WE WOULDN'T WANT TO DO ANYTHING NOW BECAUSE IF WE DON'T GET THE FIRST COMBINATION RIGHT IT MEANS THAT WE GET LESS BENEFIT OUT OF THE OTHER FUTURE COMBINATIONS.*
- 9 *That's right.*
- 10 *THAT'S WHY WE'RE GOING TO HAVE TO TRY AND GET IT RIGHT THIS TIME AND I CAN'T SAY - I CAN SAY THIS, THERE IS NO BETTER COMBINATION PROVEN APART FROM WHAT YOU'VE GOT HERE.*
- 11 *Right.*
- 12 *AND I REALLY BELIEVE THAT THE ABILITY TO TAKE THIS COMBINATION IS BETTER THAN THE ABILITY TO TAKE A LOT OF THE OTHER COMBINATIONS. FOR EXAMPLE, THESE PROTEASE DRUGS, VERY POWERFUL, VERY GOOD, BUT*

UH OFTEN ASSOCIATED WITH SIDE EFFECTS, HIGH PILL NUMBERS, DIARRHOEA, NAUSEA, COMPLICATIONS ABOUT TAKING THEM WITH FOOD, WITHOUT FOOD. WHICH MAY SUIT YOU.

- 13 *Well, my lifestyle I guess there's - I pretty well work most of the week and work some weekends, but then I'll like probably go out Friday and Saturday and socialize and party and I might go out until 4.00 or 5.00 in the morning.*
- 14 *RIGHT.*
- 15 *Um in terms of eating um don't - very rarely have breakfast um have lunch, and it can be anywhere from 11.00 o'clock until 3.00 o'clock depending on um the work I'm doing. It's not as though I feel like I'm burning up a lot of energy so I need a lot of food, but I always have a substantial meal at night. In terms of discipline in taking stuff well if I have to do it, I have to do it. I'm just sort of pragmatic about that. In terms of health um I guess the main thing health wise for me historically has been my lungs, you know, breathing, asthma, um nose um secondary has just been the stomach pains, stomach cramps, stuff like that. So, everything else is pretty good.*
- 16 *RIGHT.*
- 17 *Sleeping I can go, you know, with minimal amount of sleep for ages, but when I do sleep I'm out and I can —*
- 18 *SO, THAT'S GOING TO BE A PLUS —*
- 19 *3.00 o'clock I can go to bed in the afternoon if I feel tired and I'll be up for two hours.*
- 20 *EXCELLENT.*
- 21 *And I'll you know people have said, who have stayed with me have said that as soon as I hit the pillow I'm asleep in 30 seconds.*

What we are suggesting is that the way the interaction unfolds can be potentially applied to the development of ways in which communication between doctors and patients can aid compliance in more general application, not simply in uptake discussions.

The two major focuses of analysis – interactive sequence and roles in relation to knowledge production are realised differently here. We can see that the Doctor's elaborated turns at talk give way to the patient's elaboration of their own experience, habits, lifestyle etc. These are necessitated by the way in which the doctor establishes the course of the interaction, but the way in which they behave in this content territory is different. The patient takes a knowledge producing role, which includes the selection of topics. In contrast, the doctor takes a back channelling, confirmation of understanding role rather than one of selecting and focusing topics and approving or evaluating answers. The patient also uses declaratives extensively, uses narrative as a form of elaboration of knowledge (15), and explication (3,15) is also deployed by the patient. In short, the patient has the room and the skill to 'move around' in the interaction, and so can elaborate and construct knowledge.

This provides for a syncope of lengthy medical information and discussion and lengthy elaboration of the patient's life and habits. One can only assume that such an interaction produces a collaborative knowledge of the medical and lifeworld domains that will impact on the patient's treatment regime and his compliance.

There is still foreclosure and authority being deployed at the end of this piece of interaction, and it is framed within a set of medical needs or ideas about the patient IN RELATION to the kind of person, personality that will comply or lifestyle which will suit aid compliance. The patient is evaluating himself and is being evaluated in terms of the way his life will 'fit' with the drug regime.

The emerging stability in interactive patterns and sequence in some doctor patient treatment interactions appear to limit the degree to which an active construction of knowledge related to the experience of taking and complying to treatments is possible for patients. This potentially inhibits doctor's and patient's collaborative engagement with experiential knowledge that may or may not be central to issues of compliance.

The current study and this paper have gone some way to suggesting the way in which this kind of expanded, compliance supportive communication might be produced through a kind of interaction that accepts the value producing and encoding role of clinical discourse, and which actively works at providing opportunities in interaction to produce a collaborative knowledge, collaboratively. In one sense, what we have been able to achieve is a description of foreclosure prevention strategies in clinical encounters. In other words, foreclosure prevention might well characterise compliance supportive communication. But this means more than letting the patient talk, and more than providing information so that a patient can 'understand' medical knowledge.

The point of interactive or interdiscursive tension is not simply who gets to talk and about what, nor is it about issues of clarification of information. Knowledges and the cultural value attached to them are also interacting in these encounters. It seems clear that the kind of stability of interaction which we see in most of our data is the result of the adaption of clinical encounters and knowledges produced through a short but very effective history of critically engaging with and reconfiguring the medical encounter. There have been new knowledges and styles of interaction produced by medical encounters over the history of the epidemic. The stability of those knowledges with the power and value accorded medical knowledge mean that foreclosure of specific kinds occurs. So, the way in which knowledge production and the values and power attached to knowledges as produced interactively are what are at issue. Collaborative production of new knowledges that combine both medicine and life experience needs to be kept active in the HIV clinic.

CONCLUSION

Makoul, in drawing implications from his study of passivity in clinical encounters (1998:255), suggests that physicians can facilitate the process of "enabling people to increase control over, and to improve, their health" (quoting WHO 1986:1) by "using communication skills and strategies that encourage physician-reliant patients to exercise appropriate control during the medical encounter". Though this suggestion aims at increasing interactive control in medical encounters, the emphasis on communicative behaviour "skills and strategies" is in line with our suggestions that a kind of communication needs to be developed to support compliance. Extending this kind of idea into the HIV clinic, Moore et al. propose a collaborative model.

A collaborative model in which meanings are seen as exchanged or co-constructed, allows the patient to contribute as a kind of expert, as a meaning maker not just a consumer of meanings. Such a model is better suited to, or even necessary for, effective communication in health care. Of course there is still much to be worked out about the discursive practices of doctors and patients in HIV medicine (Moore et al., 2001: 448).

In order to produce what Moore et al. anticipate as an exchange based collaboration, we would suggest, based on our analysis, that an enhanced understanding of turn taking and sequencing in clinical encounters, and an enhanced sense of how turns at talk can be used variously to elicit discrete information or proliferate knowledge of a patient's experience (medical and other) may produce a more compliance supportive communication in the clinical encounter. The development of a sense of 'collaboration' regarding a more holistic knowledge which is brought to bear or implicated in the experience of prescribing, taking and 'living with' drug regimes is necessary. This will require an active, practice-based acknowledgment of the ways in which knowledge is privileged and valued and the way in which it might be co-produced in interaction. Such collaboration would create knowledge producing processes and thus generate 'new' knowledges shared by doctor and patient.

Implications

- Pills and Practice
- Compliance Supportive Communication

Several measures are implied by this research.

- Structural reform to the healthcare system for prescribers of complex pharmaceutical technology would allow doctors the time to more fully engage the patient's world. The threat posed to public health by drug resistance is a compelling argument for this reform.
- Consideration should be given to programmes of doctor and patient education regarding the kinds of talk that might be possible in the clinic, including skills development for both in facilitating and intervening in each other's discourses.
- *For doctors*, developing patient expertise may require changes to practice. Since 1995 the expression of HIV has changed considerably in the direction of chronic illness. This entails taking on more elements of patients' lifeworlds over the longer term. Some training is necessary in order to equip GPs with the relevant expertise to address these circumstances. Attention to how current communication practices authorize or fail to authorize patients in terms of their world would improve practice in the direction of greater adherence and better care. Attention should be devoted to how current practices develop or impede a patient expertise on living with treatment, with the aim of increasing practitioners' capacity to respond constructively to treatment morbidity and other forms of patient experience.
- *For patients*, there is a role for community-based education agencies in the development of patient expertise, so that it is capable of contributing to the exchange between doctor and patient, and so that PLWHA are better equipped to act on the conditions that impede self-care. Education should focus on providing ways in which patients can consider and present their experience of treatments to doctors. This would involve working initially with clients/patients, providing opportunities to discuss and elaborate their experience, working with breadth in terms of lifeworld discussions. Educators could then provide assistance in reformulating accounts and recounts of lifeworld experience so patients can present considered versions of these to doctors. This would produce a scaffolding process, staging the development of accounts and information, building toward accounts for use in clinical encounters. This would address the expectation that patients be able to be expansive and discursively equipped in the already foreclosed domain of the medical encounter.
- Greater use of the opportunity presented by 'monitoring' visits might be made on the part of doctors and patients, to develop the patient expertise we describe. This would consist in exploring with the patient his/her world and the *situations* and conditions that impede self-care, so that the patient is better equipped to act upon these. Consideration could be given to the use of intermittent 'chat' consultations. This would involve the establishment of a system whereby a doctor and patient occasionally devote a longer-than-normal consultation to broad ranging discussion of a patient's lifeworld that is not necessarily centred on treatment experience.

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