

# 1

## Introduction

What is curious is that when one talks to doctors about this behaviour [giving information or opinion], most claim that they use it frequently. Yet on tape one finds that the majority switch quickly from Phase III [examination] to V [detailing further treatment] with hardly a word to the patient en route. They only give the information as a prelude to termination in explanation of the nature of the prescription they are about to hand over.

(Byrne and Long 1976: 50-51)

I didn't even then have my own strategies for myself, that – I've come away from the conference thinking um I've, I've got to plan a strategy. I don't take their strategy. I'm an individual, I take their information and plan my own strategy and that's how I will survive this. Um. Not by taking other people's strategies.

(Hayden, HIV+ survey respondent quoted in Race et al. 1997: 7)

### 1.1 Decision-making in medicine - changing practice?

In their classic study of medical interaction in general practice in the UK more than 25 years ago, Byrne and Long (1976) found that there was very little evidence that doctors involved patients in making decisions about their treatments. Even among doctors who thought of themselves as sharing information and opinions with their patients, there was little evidence that this actually happened.

Has practice changed since the mid 70s? Is there still such a mismatch between what doctors profess to practice and what they are observed to do? Certainly there is a vast increase in the attention given by clinicians, researchers, lobby groups, and governing authorities to interactional aspects of medical practice, and there is a widespread view that among the different styles of medical decision-making, shared decision-making is now more popular than “either extreme” (Guyatt et al. 2002: 572), namely paternalistic approaches to decision-making and those in which doctors leave the decision-making to patients and only provide technical advice. However, some researchers argue that decision-making in practice has not changed much at all in recent decades (Coulter 2002, Elwyn, Edwards and Kinnersley 1999).

It is likely that such disagreements reflect partial and contingent change, but they also raise important issues of perspective and method. For instance, where mismatches between observation and self-report are found, such as in Byrne and Long (1976), is it necessarily that practitioners are wrong about what they do, or is it possible that the way in which the researchers construct and measure their object of study makes it difficult for them to find evidence of it?

Turning to the second quote used to open this chapter, we come to a different time – the late 1990s; a different country – Australia; a different voice – that of a person living with HIV (usually abbreviated HIV+, or PLWHA, for “person living with HIV or AIDS”); and a very different picture of the role of patients in determining how their health is managed. Hayden (quoted in the second opening quote) presents himself as an extremely active, involved, almost aggressive patient who goes to conferences about HIV, someone who it would be hard to imagine occupying Byrne and Long’s world of clinical practice.

Hayden’s self-reported approach to interacting with medical people and discourses may be extreme, but it is essentially typical of views articulated by many HIV+ people who have been interviewed about living with HIV in Western countries. But is Hayden’s description of his practice as a patient accurate? If we had the opportunity, would we observe him in practice taking information from doctors and planning his own response as he claims to do, or would he be observed, at least on occasion, taking a more passive role?

Of course these questions are rhetorical in many respects, but this itself is a useful demonstration of the fact that it is not obvious how one might gauge the giving and getting of information, or the taking and sharing of responsibility, and it does not take into account the possibility that there will be conditions which motivate people to do this differently despite holding to the same overall strategy. The fact that experts disagree about what kinds of decision-making practices doctors and patients currently engage in suggests that the framework within which such practices are compared needs clarification. The main task of this thesis is to make such a clarification.

In this thesis I will take issue with some of the ways in which shared decision-making has been conceptualised in recent research, arguing that, like Byrne and Long, the literature as a whole overemphasises decision-making as a bound event, and paradoxically retains a view of doctors' behaviour as an independent variable, with patients' behaviour as the outcome. My critique will include the way in which decision-making styles are modelled along a unidimensional continuum from "enlightened paternalism" to "informed consent", with shared decision-making positioned conceptually as a "middle way" (e.g., in Charles et al. 1999a; cf. Guyatt et al. 2002). According to this unidimensional view, both the informed and shared systems of decision-making (but not paternalism) "retain the objective of arriving at a treatment decision based on the doctor's knowledge and the patient's preferences" (Robinson and Thompson 2001: i35). It will emerge that such a polarisation of roles between doctors and patients does not capture what is meant by, and practised as, shared decision-making in HIV medicine.

## 1.2 A discursive approach

An alternative view is to take a more discursive approach, which treats medical decision-making as a type of social process or activity that differs across a *number* of dimensions from other styles of medical decision-making, as well as sharing features of social processes outside medical decision-making (cf. Sarangi 2000). The crucial feature of such a view is that it relates variation at the level of context or activity to variation in meaning. A number of schemata are available for framing this relation,

including genre (e.g. Swales 1990), activity type (Levinson 1979), discourse type (Sarangi 2000) and register (Halliday 1978), but they can be integrated around the central notions of meaning potential (Halliday 1973) and dialogism (Bakhtin 1986, Markova 1990a). Taking such a view provides the opportunity to make a detailed enquiry of what doctors and patients do, in terms of what they say and mean, when they engage in shared decision-making, when they try to close off an expectation of shared decision-making, and when they want to open such an expectation up. In this way, shared decision-making is seen as negotiated and renegotiated as it unfolds, rather than set up in advance.

### **1.2.1 What is meant in this thesis by a discursive approach**

In calling for a discursive approach I refer broadly to a range of schools and methods which emphasise the connection between the social order and language. This view holds that meanings are not “out there” waiting to be “packaged into” or “conducted through” language (Reddy 1979), and it holds that different “ways of saying” constitute different “ways of meaning” (Hasan 1996/1984).

This approach overlaps considerably with what Ford et al. (2002:5) term “discourse-functional linguistics”. Their category incorporates methods and findings which share an orientation towards “tying together discourse structures, cognitive mechanisms and patterns of grammar”. Under this umbrella they include linguists such as Bolinger, Chafe, du Bois, Halliday, and Longacre, along with sociolinguists Labov and Schiffrrin, social theorists Goffman, Hymes, Gumperz and Erickson, linguists with a particular influence from anthropology such as Duranti, Ochs, and Shiefflin, and conversation analysts such as Schegloff, Sacks, Heritage and Maynard (Ford et al. 2002). Although these traditions still have their points of conflict (see e.g., Sarangi and Candlin 2001), from a big-picture perspective they are increasingly sharing similar aims, methods and personnel.

For the present study, the most crucial aspect of this convergence is that grammar is becoming increasingly foregrounded as a resource for interaction and as

a mode of interaction<sup>1</sup>. Linguists are increasingly taking the view that grammatical choices need to be understood as being made at particular points in sequenced interaction, as reflecting where the interaction has come from and where it is heading now – hence CA’s classic question, *Why that now?* (Schegloff and Sacks 1973). As Schegloff et al. (Schegloff et al. 1996: 36) point out, “matters of great moment are missed if grammar’s order is explored as entirely contained within a single, self-enclosed organisation”. But matters of significance are also missed if grammar-in-interaction is explored without a consistent frame for reflecting on where you are now compared with where you could be – *Why this rather than that?* (cf. Garfinkel 1981). This is especially relevant in the case of shared decision-making in medicine, which has received relatively little attention in terms of grammar-as-choice. These two perspectives of choice and chain are both needed, and can be brought together by viewing grammatical choices as situated among a broader set of discourse strategies<sup>2</sup>.

The approach taken in this thesis can also be seen as part of the general tradition of sociolinguistics, if sociolinguistics is broadly conceived of as “the study of language in its social contexts and the study of social life through linguistics” (Coupland and Jaworski 1997: 1). Coupland and Jaworski say that sociolinguistics is the best single label to represent a very wide range of contemporary research at the intersection of linguistics, sociology, social theory, social psychology, and human communication studies. This is not necessarily the dominant conception of sociolinguistics, however. One approach within sociolinguistics which contrasts strongly with the position taken in this thesis (cf. Coupland et al. 2001, Bourdieu 1991, Poynton 1985) is the view that social categories such as class or ethnicity, or professional/ lay roles, determine ways of speaking in a unidirectional manner. My criticism of this view can be extended to sociolinguistics’ tendency to reify many

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1 Of course there has been a consistent line of linguistic work within this tradition (including Boas, Sapir, Whorf, Malinowski and Firth, from the 1890s to the 1960s).

2 The term ‘strategy’ should not be taken to indicate that such choices are a product of conscious deliberation. The particular configuration of multiple grammatical selections in any clause is usually below speakers’ conscious control, thus is not intentional but may be said to be a motivated choice, in that it is habitually used by that speaker to convey a certain meaning, or is associated with a certain community or social function.

aspects of context or situation as a ‘constant’ held firm against the ‘variable’ of language behaviour, a view which Coupland et al. (2001) describe as early Labovian and as drawing heavily on Parsons (1951). A similar view, in which personality is a ‘constant’ and health behaviour is the ‘variable’, underpins the way in which many key practices in health care have been studied, including treatment decision-making, and ‘compliance’ (treatment-taking). This includes research aimed at linking socio-demographic variables with patient preferences for participation style in decision-making (although consistent effects have not been found). It motivates the construal of compliance as a consistent personal attribute rather than a situated practice (Lerner 1997), despite evidence that adherence varies as people’s lives change (Spire et al. 2002). This is particularly pertinent in HIV medicine, where adherence to treatment regimens is crucial but where the biggest communication problems between people living with HIV and their health care workers revolve around discussing medications and adherence (Jones et al. 2000, Race et al. 2001).

It is not a peculiarity of sociolinguists and medical research that they tend to focus on the internal unavailable rather than the external and dynamically interpreted social sign. From a number of perspectives, including the grammar, our culture models *deciding* as internal, mental, individual and, if not static, then “state-like”<sup>1</sup>, where perhaps it would more helpfully be modelled as externally displayed through talk, and thus interactive, intersubjective, and always critically dependent on the particular discourses through which it has been projected and realized. This is to claim that medical decision-making should be seen not as the simple selection of treatment options, but as a negotiated process of constructing options and valuing them through language and other symbolic resources. It is also to claim that decision-making is much more than the particular ‘forms of words’ in which decisions are realised – indeed, it is very often difficult to tie decisions down to a single location in a text or interaction. In particular, it is a claim that if we attend closely to the

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<sup>1</sup> These perspectives include the grammar of verbs such as ‘decide’ in English; the decision theoretic tradition of research in medicine (see ch 2); and the psychological and some sociolinguistic traditions that treat ‘patient characteristics’ such as preferences for treatment or preferences for participation levels as fixed attributes of a person rather than at least in part locally negotiated and constructed in interaction (Myers 2000).

wording through which decision-making in medicine is practised, we can make important hypotheses about other levels of organisation in language, interaction and social structure (cf. Coupland 2001).

It might reasonably be pointed out that medical consultations and decision-making comprise much more than the verbal mode, including gaze, gesture and proxemics (Heath 1992), the material actions that clinicians perform on patients as institutional objects (Sudnow 1967, Hak 1999), and visual and multi-modal displays of results on the computer. It is beyond the scope of this thesis to take these modes into account in any systematic way, since it was not possible to observe these aspects in my study. It might also be argued that shared decision-making comprises more than social interaction, and that it needs to be considered in terms of institutional practice and professional practice (Sarangi and Roberts 1999), along with its role in reproducing and transforming the social order more broadly (Fairclough 1995a). These approaches will inform the argument of the thesis, and they will be introduced as they become relevant to the discussion at hand.

### **1.3 Key themes and analytic resources in this research**

Shared decision-making in medicine is a highly complex discursive practice, in which small differences in the wording or sequencing of messages may result in important changes to their meaning and to the construal of the context. Collaborative decision-making is only possible where alignments between the grammar, semantics and context can be shared by patients and doctors. Put another way, where participants are able to align with each other discursively, this *may* allow them to come to a shared position. In order to describe and evaluate shared decision-making we need instances of how this works and issues around which it is centered, both of which this thesis provides.

Before going much further in outlining theoretical issues, let us get our bearings by looking at one instance of decision-making and its discursive realisation, taken from the data set which I will describe in chapter 3. The consultation excerpt below serves as a point of departure for identifying clinically relevant concerns and previewing how they can be treated discursively. This consultation, between a man

with HIV and his GP, starts at the point that they turned on the audio-recorder, with a brief recap of what has gone before.

Extract 1 from consultation 62:

- 1 D ... basically I've just given you the results and ah your viral load's undetectable, which is incredible.
- 2 P And I thought it was actually- just repeating what I said there- that was fucking good news, okay. It's quite amazing.
- 3 D It's incredible.
- 4 P I'm really shocked because I was resistant, so I was thinking I'd stick to one thousand and maybe I'd lose it. I was expecting actually
- 5 D That it would creep-
- 6 P worse results.
- 7 D That it would creep up, yeah. I have to say, um, I'm really quite stunned by them as well. Because it did sort of creep up a little bit on the second reading which
- 8 P Yeah. That's why I was expecting it.
- 9 D Yeah.
- 10 P So what does it mean? What happens now? Stick on the drugs of course. Stick to the drugs.
- 11 D Yes, just stay on the drugs. Um, I really- we don't have enough information to know, um.
- 12 P Okay. Do you
- 13 D how long it's gonna last.
- 14 P Okay.

### 1.3.1 Negotiating clinical goals: viral load as technical token

Perhaps the most striking feature of this extract is the almost palpable excitement and positive affect at the beginning, shown in the interactants' use of epithets such as *incredible* (turn 1), *amazing*, *fucking good news* (turn 2), and so on, whose meanings are readily accessible to the outside reader, along with other aspects of the language of this interaction which are not so readily interpretable or so directly evaluative for a general audience, such as *undetectable*. The hopefulness of these two people echoes the excitement and optimism of the mid-late 90s within the HIV community (at least in the West) (Berger 1996). During this period – the period of data collection for my study – the practice of HIV medicine was becoming much more focussed on controlling underlying disease mechanisms (viral replication) rather than symptom control; HIV was in the process of being transformed from an acute terminal disease to a chronic but manageable illness.

Two key technical advances held the spotlight in this process, viz the suites of drugs designed to stop HIV replication – known as highly active antiretroviral



treatment or HAART, or as combination therapy – and the blood tests that had been developed to measure viral replication – known as the viral load test. The immediate aim of HAART is to reduce viral load. The above extract shows a doctor and patient celebrating what is construed as a very good result, as a surprisingly good result. This implies that an understanding of the referential and evaluative framework of the test is shared by the patient and the doctor, i.e., that what counts as a good result, what is likely to effect a good result, and what action is implied by a good result, all count as knowledge which the both the doctor and patient have access to.

But that simple analysis would be wrong. In fact, for patients to discursively manipulate technical tokens such as ‘viral load’ and to agree with their doctors about particular instances of results does *not* guarantee that the framework for interpreting viral load is shared by patients and doctors. This issue will be brought out in later chapters, particularly chapters 6 and 7, where I will argue that viral load as a concept is multiply coded, and that these different codings of viral load index different discourses of HIV medicine. This is essentially treating the technical token ‘viral load’ in relation to its ideational semantics, and showing how its ideational value (i.e., what viral load is taken to represent), varies with small-scale shifts in the context being construed. In order to demonstrate and evaluate such a claim, we need a fairly powerful way of characterising context and its relation to language, an outline of which appears in chapter 5.

The payoff for studying the way that doctors and patients negotiate technical coding is that we can clarify the “semiotic networks relating signs and significations” that ten Have identifies as a basic requirement for diagnosis (ten Have 2001: 252). It also has equally important payoffs in planning and reviewing treatment (Adelswärd and Sachs 1996, 1998). In HIV health care it is important to understand the equivocal role of viral load in relating both subjective and objective discourses of health to clinical goals and interactive strategies for achieving them. Analyses of treatment decisions based on such a view of viral load can help explain why unexpected misunderstandings and misalignments between doctors and patients occur. These misalignments are significant in their immediate context, but also because they get in the way of building the kind of long-term relationship in which treatment selection, implementation and revision can be most effective. In the extract above, the results

are good and there is no conflict about how to evaluate them, only some uncertainty about how best to capitalize on them (turns 10-14). In other texts analysed, however, significant though often submerged conflicts and misalignments occur. Such tensions are central to the analyses of consultations in chapters 4, 5 and 6.

### 1.3.2 Asymmetry and its discontents

After the optimistic tone, perhaps the next most striking feature of the above consultation is its symmetrical nature as a dialogue. Many text extracts in studies of doctor-patient interaction display a notable asymmetry of interactive roles, where typical patterns consist of doctors asking questions and patients providing answers, or doctors providing explanations/directions and patients being restricted largely to backchannelling with *mm-hmm* and *okay* and so on. Yet in the above interaction patient and doctor seem to make similar types of contributions and seem to contribute a similar amount of talk which progresses the meaning. The first part of the interaction shows both doctor and patient construing themselves as valid commentators on the viral load, for instance. Shortly afterwards, the patient asks an unremarkable question<sup>1</sup> for a patient, opening up the space for deliberating about treatment as a response to clinical tests. But then the patient answers the question and closes up the decision space, a move more typical of doctors: *So what does it mean? What happens now? Stick on the drugs of course. Stick to the drugs* (turn 10).

Such a discourse practice would be considered typical for doctors, but unusual for patients (Byrne and Long 1976, Elwyn et al. 2001). It is unclear from this single extract how complete the symmetry is between doctors and patients in HIV medicine. An additional extract from the same consultation helps to situate this issue. The consultation continues as follows:

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<sup>1</sup> Notwithstanding claims, by researchers such as West (1984) and Frankel (1979), that patients ask few questions.

## Extract 2: from Consultation 62 (continuing from previous)

- 15 D ((phone rings)) Just excuse me a minute  
16 P Sure.  
17 D ((speaks on phone))  
18 P Hey, it was printed on first of April - maybe it's April Fool's Day! ((laughs)) Ah, so the next question I'd ask is, okay, but my CD4 count's actually risen quite a bit as well, I mean I, it was thirty when it was on the lowest ebb.  
19 D Yeah.  
20 P But is there any way of boosting the um immune system now?  
21 D Um, the- the kind of drugs that would boost the immune system are immune modulators and the- um, the one that's used to most commonly is um interleukin 2.  
22 P Mm, I remember I was-  
23 D which is- which is injections, sort of thing.  
24 P And you get a reaction to it like a flu.  
25 D Yeah. But there's going to be a trial for that a bit later this year.  
26 P For people who've got not detectable- what, for people who've been on these drugs, the trial?  
27 D I don't- I'm not a hundred percent sure what the entry criteria's going to be.  
28 P Cos I thought they were trialling this, y'know, like a couple of years ago.  
29 D Yeah, that was for a higher CD4 count at that stage.  
30 P Right.  
31 D Um, but there's- there's a question mark about it because, um, just to simplify things, basically um, when, um, you start off with- if you start off with a normal T-cell count, there're individual T-cells that are primed to deal with specific infections.  
32 P Yeah.  
33 D Now, when your T-cell falls, um if- if you- if you lose er all the - cells for a specific- against a specific infection, then um, they may not come back.  
34 P But that's a THEORY though, isn't it?  
35 D It's a theory and, there's- there's some evidence to suggest that over- over time um, that it could- it could- there could be regeneration.  
36 P Y'know I would  
37 D So that's- but simply increasing the- the level of the- cells initially, what it does it just multiplies the existing pool that there is.  
38 P Right. ... Cos it- there must be a memory, sort of, like um a DNA memory molecule or something like that which memorises what certain specific T4-cells or fighter cells do,  
39 D Mm.  
40 P and it can- and it just needs to- I don't know, maybe that's a- um, I'm theorising myself, hypothetically.  
41 D ((laughs)) Well, I think there is some evidence to suggest that there is reformulation of previously lost lines, but it takes time for that to happen.  
42 P Takes a long time.

It is fairly obvious from the first extract that this interaction does not fall into the category of paternalistic decision-making. With additional data we notice that there are a number of ways in which this interaction does not sit well with a model of shared decision-making in which the doctor's *knowledge* and the patient's *values* are brought together, since clearly this patient is contributing to the knowledge work,

and the doctor is contributing to the value work. Nor would it be fair to say that this is an example of the doctor performing merely as a technical advice-giver for a patient who decides on his own.

In fact this consultation demonstrates what I will argue appears to be a local norm for HIV medicine. Across a range of features, the patterns of interaction and coding in the present corpus are quite different from what other studies of medical interaction have found. In this one example, the patient leads a shift in topic/phase, from evaluating the test results to inferring what treatment action to take, although such a move is normally considered the province of doctors (Ainsworth-Vaughn 1998). The patient hands down the decision about what treatment action to take, although this move too is normally considered the province of doctors (e.g., Byrne and Long 1976). And the patient moves onto the topic of additional treatments and treatment rationales, and challenges the doctor's technical causal reasoning about this, which is a pattern of responding to doctor's explanations of their claims which patients have been observed to eschew (Aronsson and Sätterlund-Larsson 1987). The patient represents himself in the role of the knower (turn 10), commentator/evaluator (turn 2,18), planner of the logical and topical flow of the dialogue (turn 18), theorist (turn 40), and expert in the epistemological status of medical explanations (turn 34).

There are other many other instances which stand out against the backdrop of the literature on doctor-patient interaction, and these will be drawn out in future chapters, but one of the most striking is that an unusually large proportion of time is spent reciprocally engaged in discussion within what appears to be the 'socio-relational frame' (Coupland et al. 1994) rather than the 'medical frame', although it is argued in this thesis that such dichotomies too need to be re-examined in terms of local norms and local realizations for HIV medicine and for shared decision-making (cf. Sarangi 2000). For instance, extended discussions of experiences and plans with respect to the gym, and with respect to mardi gras events<sup>1</sup>, occur in a number of consultations in this study. Such discussions can be reinterpreted as directly within the medical frame if the missing cohesive link of interactions between recreational drug use and prescribed drugs is inferred. Or even without this interpretation, such

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<sup>1</sup> A gay pride celebration cum political demonstration, including street parades, parties etc.

discussion can be seen to fulfil an important tone-setting function (Hasan 1999) which helps to configure the interaction as a whole in terms of a particular tenor.

Many of the features discussed so far tend to be associated with conversation rather than professional discourse. As several scholars have pointed out (e.g., Fairclough 1995a, S.Candlin 2000, 2002), the presence of such features does not necessarily indicate that the positional power of the clinician is proportionally reduced; it may merely have 'gone underground'. But nor does this mean that there is a constant level of power which is merely relocated from the explicit to the implicit domain, as if it were principally a quantitative issue of how much power a professional has, versus the layperson in a professional interaction or in an institution more generally – as Foucault (Foucault 1977) points out in his discussion of “capillary power” and its constant changing of hands. These apparently marked, or changing, ways of doing medical interaction have important effects across a range of dimensions to do with the opportunities that patients have for participating in decision-making about their own health management.

### **1.3.3 Agency and identity**

From the brief examination of the items of data and research issues undertaken to this point, it is already possible to suggest that viewing patient participation as a gradable unidimensional practice is problematic. From a more detailed review of the literature (in chapter 2), the social category of agency will emerge as one of the key dimensions of meaning through which HIV medicine achieves its character, and which is also crucial in defining shared decision-making. In examining this dimension of decision-making practice, it will be necessary to explore the degree to which doctors and patients construe themselves and each other as active agents in the activity of decision-making and its projected actions and events – dispensing, taking pills, remembering to take pills, interpreting bodily experience as side effects, reviewing progress and so on.

There is evidence from health outcomes research that when patients construe themselves as agents of their own health and healthcare they are more likely to

benefit from treatment and maximise adherence (Greenfield et al. 1988, Kaplan et al. 1989, Schulman 1979, Stewart 1995, Szabo et al. 1997). However, these findings must be viewed with caution because the relationship between patient agency and institutional authority is complex and far from clear (Race et al. 1997, Peräkylä 2002, Gattellari et al. 2001). For instance, enhancing patients' agency may result, not surprisingly, in fewer patients initiating the treatments that their doctors would ordinarily recommend (Protheroe et al. 2000).

A central argument here is that the degree and type of participation – both in deciding about treatment, and in doing the treating – can be productively illuminated through an analysis of the semantics of agency. Underpinning this is the view that individuals' sense of self is constructed and reflected in verbal interaction, thus 'selves' are inherently relational and discursively negotiated (Potter and Wetherell 1987; Harré 1979, 1991). This view can be elaborated with a key insight from discourse-functional theories of language, namely that grammatical patterns in any language or variety of language systematically code meanings about the degree of responsibility, centrality, benefit, and so on, which social interactants purport to have in relation to events and states of affairs in which they find themselves, and on which they reflect verbally (Halliday 1973). These grammatical patterns are a key semiotic resource on which the development of a sense of self, or selves, is based; thus discourse analysis aimed at examining the construction of identity needs to pay close attention to grammar (Butt 1991, Thibault 1993, Lemke 1995), as does discourse analysis aimed at examining the construction of ideology (Fowler et al. 1979, Chouliaraki and Fairclough 1999, Hasan 1996/1986). Verbal interaction is always simultaneously a reflection about the world and relationships in it, as well as an on-line construction of such relationships, starting with the speech roles of speaker and addressee, and moving outward to the construction and maintenance of more long-term social relationships (Goffman 1981, Malinowski 1978/1935, Halliday 1978). Such an approach echoes Schegloff et al's (1996: 38) identification of grammar as a *resource* for interaction, an *outcome* of interaction and a *mode* of interaction.

In order to examine the degree to which a sense of the patient's self as agent is available, encouraged, and taken up in HIV medicine, again it is crucial to study the

discourse strategies in detail. It will be necessary, here too, to take a multidimensional approach. A brief and simplified illustration can be drawn from the data extracts given above to lay the ground for what will be developed later. Using the method of identifying and interpreting agency most commonly employed in text analysis of agency (e.g., Fowler et al. 1979, Fairclough 1995a, Duranti 1994, Martin 2000b), the doctor and patient in Extract 1 would not be considered as very highly agentive. The doctor is mapped into the role of grammatical Agent in an explicit fashion only once: in line 1 the doctor reports himself as having “*given [the patient] the results*”, while the patient is mapped into the patient role twice, albeit somewhat ambiguously in both cases “*lose it*” (the previous result of 1,000), and later in line 10, when he talks about “*stick[ing] to the drugs*”. It is the HIV treatment, and goals and effects of treatment, which have the highest grammatical prominence as Agent – six times in this short section – as being the external agent of events. (In extracts 1.1 and 1.2, totalling 95 clauses, there are 27 clauses of the Material Process type, which according to standard Systemic Functional Linguistics (SFL) practice is the type of clause where an Agent may be specified, excepting unusual cases. Of these 14 are effective clauses. Effective clauses may have only the feature Agency but leave the Agent implicit or unspecified. Thus 14 out of 95 clauses in this extract construe events as having external agency, through the grammatical categories used typically to represent it, namely ergativity and transitivity.)

I will revisit and critique this type of analysis in more detail later in the thesis, but even in this simple illustration we can see that this type of analysis leaves us with a problem. Most readers would agree that it would be misleading to argue from this that treatment was construed as *more* agentive than doctors, patients, or the institution of medicine itself, but this does not mean that the analysis of lexicogrammatical choices is not important in explaining how agency is portrayed here, or more generally. The way in which the patient in Consultation 62 gives off a sense of acting to affect the shape of the consultation, eliciting and producing knowledge, and negotiating an agreement, can be crucially informed by a close analysis of lexicogrammatical choices, if we expand the range of choices examined,

and if we view them as variable ways of realizing a multidimensional sociosemantic category of agency.

#### **1.3.4 Alignment of participants and discourses**

If it is clear that patient participation is not a zero-sum game, it should also become clear that no amount of increased participation from patients, or enacting of a highly agentive self on the part of patient or doctor, can guarantee that decisions reached are in fact joint decisions. In practice, maximising patient agency and participation in decisions needs to be complemented with a way of maximising alignment between doctors and patients. This means that research on shared decision-making will need to be able to separate these dimensions out as distinct principles, even if they are always integrated in practice. In particular, doctors and patients need to be able to identify the various discourses that each other may be orienting to at any one time, and to develop ways of flagging shifts and conflicts, in order to continually negotiate and maintain alignment (Tannen and Wallat 1993, ten Have 1991).

The concern with participant alignment has developed from within Conversational Analysis (Goffman 1981, Heritage 1984, Maynard 1986, Drew and Heritage 1992, Tannen and Wallat 1993, Peräkylä 1995, Heritage 1997). Arguably this work has tended to focus on what might be called surface-level aspects of verbal interaction, usually taken as markers of alignment in a much deeper sense. Such features include the degree to which speakers might either interrupt each other or wait till turns are quite complete, including whether backchannelling/continuers are provided. There is an implication in these approaches that 'what gets aligned' is one unified self (social actor) with another unified self, or in some cases one body (Heath 1986) with another, in terms of aligning visual, oral, proxemic attention with the activity or attention of another. But what of the problem of interactants signalling to each other their mutual alignment while actually talking at cross purposes, which they may or may not later discover? Or the situation where solid alignment between interactants with respect to one issue or frame fails to extend to other issues or frames? For instance, a doctor and patient's mutual signalling that a particular viral load result is good may mask the fact that their frameworks for evaluating viral load



are not aligned. By contrast, a doctor and patient who contradict each other about how to interpret a result may be better aligned, or end up being so – it is important to stress that alignment, as it is discussed in this thesis, is not synonymous with agreement, or with the display of mutual affection or empathy. In HIV medical decision-making, and in other areas, what seems most important to examine and account for is the mutual alignment of participants to each other in terms of their relative orientation to different discourses of health and health care.

In terms of such an approach, our extracts from Consultation 62 would be characterised as having a high level of participant alignment. One key indicator of this occurs in line 5 of extract 1, when the doctor “interrupts” the patient.

P I was expecting actually  
D that it would creep-  
P worse results.

For doctors to interrupt patients has been discussed as way of controlling patients and “excluding their concerns” (Waitzkin 1991), but in our example above, which is not atypical of the present corpus, the doctor does not appear to be controlling or excluding the patient. When considered with its co-text (the surrounding turns at talk) it can be seen that the doctor supplies a viable projection which could complete the patient’s sentence here (Goodwin 1981, 1979). The patient finishes off his own sentence with a different construction, but one which is grammatically and semantically compatible with the doctor’s version. There is a sense of concurrence and empathic anticipation (cf. Goodwin and Goodwin 1992) created by this type of “interruption” which suggests that the interactants here are well aligned in their view that this is a context of evaluation/assessment, and in their interpretation of the complex semantics of viral load and its implications. They are also well aligned in their tracking of turn design and its relation to grammatical constituency (Ford et al. 2002, Goodwin 1979, 1981) which they exploit here in order to create a joint position. But this is, of course, not always the case, and surface indicators of alignment are no guarantee that misalignments have not occurred or are not about to occur. The interplay between displays of alignment and what such displays are taken to index (cf. Linell 1995) is addressed in chapter 6.

## 1.4 The elusive (shared) decision

Despite a reasonably high level of uncertainty and disagreement about what constitutes it and how prevalent it is, shared decision-making is a valued feature of HIV medicine (McInnes et al. 2001). In a recent Australian health survey of people living with HIV, most participants reported having a “cooperative relationship with their doctor, with joint decision-making being a common aspect of the relationship” (Prestage et al. 2001: 58). In conjunction with other evidence from surveys and observational studies (see chapter 2), it seems that HIV patients value getting advice from their doctors, not just information, as part of a process of making joint decisions. This seems to echo the situation described in Candlin and Lucas (Candlin and Lucas 1986, cf. Silverman 1997, Sarangi 2000) although HIV doctors seem to be under much less pressure to conceal their advice *as* information, in situations where the patient’s HIV+ status is established.

More generally, the above discussion of themes and resources and their location in an overall model of meaning potential may be taken to suggest that I am taking decision-making to be an unproblematic activity, whereby instances of decision-making can easily be identified and separated in a text or interaction from activities which are not “decision-making”. In fact even a cursory inspection of my data make it clear that such a view is not supportable. A brief demonstration requires revisiting part of the extract given above:

### Extract from Consultation 62 (repeated)

- 8 P Yeah. That’s why I was expecting it.  
 9 D Yeah.  
 10 P So what does it mean?  
     What happens now?  
     Stick on the drugs of course.  
     Stick to the drugs.  
 11 D Yes, just stay on the drugs.  
     Um, I really- we don’t have enough information  
     to know, um.  
 12 P Okay. Do you  
 13 D how long it’s gonna last.  
 14 P Okay.

Where is the decision in the consultation 62? And who is it made by? Is it a shared decision? If so what roles do the different participants play? We can answer the first question, tentatively. It is likely that the reader who has read the longer extract or the whole consultation would confidently say that there is a treatment decision made at some point, namely the decision to stick to the current drug regimen; there is no evidence of this decision being made or revisited after this section, so it is probably made during this section. The answers to the other two questions are more equivocal. We could mount various arguments in favour of the patient's exhortation at Turn 10, clauses 3 and 4, to stick to the drugs, the doctor's response to this exhortation at Turn 11 clause 1; both; or something else. We could argue that the patient had made the decision, and the doctor had merely confirmed or ratified it; or we could argue that it was too minimal an activity to be called shared decision-making or even an instance of a decision at all.

The problem for the academic attempting to analyse decision-making is that many, if not most, of the instances of ongoing review and re-commitment to treatment in the samples of HIV decision-making considered in this thesis are just as equivocal as the one above.

This is not a new phenomenon (Boden 1994, Atkinson 1995), but it has not been adequately acknowledged in currently dominant models of medical decision-making. There are a number of implications of this phenomenon for the present study. Since the reader needs to know what happens after the "decision main event" in order to identify the temporal/sequential location of the decision main event in a consultation, and since this must be true to some extent for participants as well, there is an important sense in which decisions and their parts are only identifiable retrospectively, not on-line. At the same time, it is not that verbal contributions do not have a strong predictive value with respect to the presence and phasing of consultations, as it unfolds. This is a difficult paradox to work with, but it points to the importance of a logogenetic account such as that of Markova (1990b) which characterises utterances as Janus-headed, looking forwards and backward simultaneously in the unfolding text/context.

The reader's (and I would argue the participants') expectations with regard to agentive roles for the situation or activity type they are engaging in are important determinants of how exchanges such as turns 10 and 11 are interpreted, so it is important to build into the analysis an account of how the speaker always intrudes into the speech situation. To get a sense of this, if we swap the participants' utterances, we are arguably much less likely to construe the doctor's turn as eliciting a recommendation or ratification from the patient<sup>1</sup>.

10 D So what does it mean? What happens now? Stick on the drugs of course. Stick to the drugs.

11 P Yes, just stay on the drugs. (imaginary reconstruction of data)

The nub of a treatment decision is often like the one presented here – small and insignificant-looking. Or indeed there may be no nub at all, as is the case in what we might consider a “potential decision” in the extract shown: in turn 12 the patient raises the question of treatment to boost the immune function, alongside the drugs he has been taking to control viral replication, and the doctor describes a certain treatment considered to perform that function, yet the decision as such never gets off the ground – discussion skirts around it, and no “decision” is made to try the treatment, or to explore the possibility further, but no decision is explicitly made to abandon such treatment either. An adequate model of decision-making needs to take into account such false starts, do-nothing options and zero-realization decisions, often left out of analyses (e.g., in decision theory), and so these less explicit aspects are incorporated into my model in chapter 5.

Finally, it is important also to be able to handle aspects of decision-making-as-process that do not get textualised, as well as latent textual patterning. These point to the importance of bringing ethnomethodological approaches together with text analysis, as well as the importance of careful contrastive interpretive accounts.

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<sup>1</sup> I have run experimental tests of this hypothesis in lectures, and the “blinding” effect does appear to exist.

## 1.5 Summary of this chapter

Although there is already a large body of work that has produced important insights on medical interaction from a range of perspectives, including anthropology, sociology, health care research, and linguistics, there are still a number of problems which make it difficult to interpret research on decision-making and integrate it into practice (Kravitz and Melnikow 2001, Braddock et al. 1999). As a result, what looks at first to be a well covered research field in fact has many unanswered questions and prematurely answered questions, and there are concerns about what is feasible for the future (e.g., Kravitz and Melnikow 2001).

This thesis argues that what is needed at this point in the research agenda is a re-examination of decision-making as social practice, looking at instances where it is held to be collaboratively undertaken in order to draw out in an empirical but nuanced way how shared decision-making is achieved, and the conditions under which it varies. There is a need to be able to talk about a wider range of dimensions of the process of negotiating decisions and decision styles, with particular attention to the details of their linguistic realization. As a contribution to this agenda, this thesis offers a study of shared decision-making about treatment between patients with HIV and their doctors. The immediate aim is to help clarify models of shared decision-making, which may in turn contribute to better clinical practice and better professional and peer development in HIV and other fields. A parallel aim is to contribute in a small way to a more contextually sensitive account of the construction of agency in social interaction. To this end the research is guided by the following six broad research questions.

1. How does the process of arriving at an HIV treatment decision unfold as a collaborative process between the participants, including explicit decisions and implicit decisions?
2. How do doctors and patients construe and enact different kinds of agentive roles within treatment decision-making?

3. How do doctors and patients make sense of viral load results in planning and reviewing treatment?
4. Through what discourse strategies are treatment choices constructed and by whom? By what method of development are choices distinguished, e.g., through tropes of preference, effectiveness, tolerability?
5. What kinds of interactions are there between the above issues – e.g., do patients' and doctors' agentive roles change at different phases of decision-making, or when decisions are about different types of treatments?
6. How might the description of doctor-patient interaction as linguistic/discourse practice be useful for gauging and enhancing the social practice of shared decision-making in medicine?

## **1.6 Plan of following chapters**

Chapter 2 calibrates dominant models of doctor-patient decision-making against empirical and perspective pieces from health research and relevant sociological and sociolinguistic lines of enquiry.

Chapter 3 outlines the methods and data of the present study.

Chapter 4 demonstrates the centrality of the social category of agency in research on shared decision-making in HIV, and considers how social theory and linguistics might be brought together to help to clarify the role of agency and the resources used in its expression. The notion of meaning potential is explored as a way of teasing out different levels of interactive patterning that construe agency.

Chapter 5 pursues the analysis of agency at the level of context, as one of the contextual parameters which characterise HIV treatment decision-making as a specific institutional, medical context. The context is also described more generally in Systemic Functional Linguistics (SFL) terms (Halliday 1978, 1985; Hasan 1985a, 1995, 1999; Butt 2000b), drawing on the constructs of Field, Tenor and Mode,

suggesting that definitions of shared decision-making must be responsive to its variable realizations.

Having characterised the contextual meaning potential of shared decision-making and agency, chapter 6 presents a networked description of how doctors and patients *represent* each other semantically as social agents or potential agents. The network, which develops work by van Leeuwen (esp. 1995, 1996) and others, draws together the key textual resources HIV patients and their doctors in this corpus appear to mobilise for construing and enacting agency in decision-making. In the second part of the chapter this framework is used to explicate the dynamic negotiation of agency and of particular treatment choices in extended text extracts, focussing especially the divergence and convergence between speakers and their perspectives from moment to moment, and the cumulative result.

Chapter 7 draws out the key findings and briefly outlines their implications for reviewing and planning HIV treatments, for modelling shared decision-making in future research, and for professional development and peer/patient development. Some comments are also made about the usefulness and generalisability of the discourse analytic tools used in the study.





## 2

### **Models of shared decision-making in medicine**

#### **2.1 Aims of this chapter**

The quality of doctor-patient communication has been shown to influence outcomes in HIV medicine and elsewhere. Increasingly, it is considered essential that doctors and patients both participate in making decisions about the patient's health care. There is a growing body of literature describing joint decision-making and suggesting guidelines for achieving joint decisions. But, as I will describe in this chapter, very little of the literature relates descriptions of medical decision-making as a social process to the way in which patterns of verbal interaction realize or foreclose on joint decision-making.

This chapter reviews key models of doctor-patient decision-making that inform medical practice, and relates them to relevant empirical findings about what fosters joint decision-making and what effects it has on clinical management. These two strands of research are further related to relevant sociological and sociolinguistic lines of enquiry. The review does not exhaustively cover this multi-disciplinary territory but sets out the most influential positions in order to:

- a) ground the present study in the immediate concern of enhancing patient wellbeing
- b) ensure an understanding of those institutional practices of medicine necessary for research on decision-making
- c) show what kinds of models of language and interaction are explicitly or implicitly drawn on by researchers and practitioners

- d) outline how a more explicitly discursive model might reinterpret findings and identify important research directions, some of which are taken up in this study.

The review is not limited to studies of HIV medicine, but I summarise the implications for people with HIV and their doctors in section 2.3.4.

## **2.2 Trends in doctor-patient interaction and the role of decision-making style**

According to many observers, doctor-patient interaction is becoming more of a 'partnership', 'collaboration' or 'therapeutic alliance' (Elwyn, Edwards and Kinnersley 1999, Elwyn, Edwards, Gwyn and Grol 1999, Robinson and Thompson 2001, RPSGB 1997). Most observers see this change as an inevitable shift in power and social control (Kravitz and Melnikow 2001, Lupton 1997, Coulter 1997, Epstein 2000) though not all see it as a wholly positive one. Some argue that elevating the patient's status diminishes the expert status of the doctor, and promotes a so-called 'postmodernist' rejection of the possibility that one course of action is better than another in absolute terms (Smith 2002). A competing criticism is that the rhetoric of partnership between patients and doctors is a case of 'synthetic democratisation' (Fairclough 1992), in which institutional and professional power is wielded through more implicit means and therefore becomes harder to deflect (Silverman 1987). The majority of observers, however, see this emphasis on greater partnership as positive (Stewart et al. 1995) or potentially positive (Gwyn and Elwyn 1999), because it produces positive outcomes for patients in terms of their understanding about treatment (Donovan and Blake 1992, Edwards and Elwyn 2001), satisfaction with care (Roter and Hall 1993, Stewart 1995), decisional conflict (O'Connor et al. 1999), adherence to treatment (Haynes et al. 1996), and in some cases treatment outcomes (Greenfield et al. 1988, Kaplan et al. 1989, Orth et al. 1987)<sup>1</sup>. The rapidity of this trend can be shown by

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<sup>1</sup> Reports of 'positive effects' such as increased acceptance of or adherence to treatment are in some cases reinterpreted by other observers as unnecessary medicalisation (Illich 1975, Rosengarten et al. 2000). It is outside the scope of this thesis to open up this debate. It is also outside the scope of this thesis to clarify empirically whether joint decision making achieves greater treatment adherence, or any other particular benefit, or whether it has any negative effect on the quality of decisions or treatment.

juxtaposing the above summary against a quote from Hahn's early work on the subject only twenty years ago (Hahn 1983: 49):

...the provision of information and choice to patients is thought to be superfluous, wasteful, and often resulting in poor decisions ... the patient's autonomy, as a goal of intervention itself, is not commonly valued, if recognized. Patients are thought not to want to know or to decide.

Coulter (Coulter 1997) describes the evidence for benefits from shared decision-making as "sparse", and asks for more controlled studies of decision-making styles. Elwyn, Edwards and Kinnersley (1999) take a similar view about the uncertainty of benefit but argue that this is because shared decision-making has been too loosely defined to support specific evidence. Elwyn and his colleagues are cautious about interpolating the more general evidence for "effective communication" and "participatory styles of consultation" as evidence that shared decision-making has the same benefits, and no doubt they are right to be wary (Wensing et al. 2002). However, it would be wrong to imagine that "participatory styles of consultation" and the other variables that do have reasonable evidence of effect would not have some constitutive role in shared decision-making<sup>1</sup>, and so I am going to treat them as evidential 'ramps' that lead up towards evidence about decision-making style. Linell and colleagues, for instance, take a similar view, describing the ideology of "partnered care" as implying "informed decision making" (Linell et al. 2002).

## 2.3 The benefits and motivations of shared decision-making

### 2.3.1 Benefits

Key studies that establish the benefits of shared decision-making and related aspects of consultation style are presented in Table 2.1. The classic work most often taken as evidence of benefits in health outcomes is from Greenfield and colleagues (Greenfield et al. 1988; Kaplan et al. 1989). These studies, which focussed on diabetes

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<sup>1</sup> Compare Candlin and Lucas's (1986) observation of the discursive similarities between counselling and other therapies that despite the stated aims of counsellors not to provide advice, particular types of talk and sequences of talk are interpreted as advice by their clients.

management, showed that certain aspects of doctor-patient communication, including the amount of patient talk compared with the amount of physician talk, were consistently associated with "better health", whether it was measured physiologically (blood pressure or blood sugar), behaviourally (functional status), or more subjectively (evaluations of overall health status).

One way to interpret the benefits of shared decision-making is to assume that it leads to a better decision. The chief argument here is that a more personalised rationale for selecting treatments will usually result in a more appropriate, sustainable regimen (Donovan and Blake 1992, Benson and Britten 2002). This is an especially important factor in HIV, where treatments are highly toxic and demanding to maintain – the most recent Australian study reports that about half its respondents were taking more than ten pills per day (Prestage et al. 2001). Given that approximately half of these people will be in a clinical trial at some stage (Prestage et al. 2001), it is important to note that the ideology of clinical trials, in which patients are considered in terms of their *eligibility* for treatment, sets up some potential conflict with promoting a more personalised choice of treatments in terms of their *suitability* for patients (Candlin et al. 1998, Brown et al. in press).

On the other hand, the benefits of shared decision-making can be seen as benefits of being involved in the *process* of decision-making, regardless of whether the same decision would have been made by the doctor alone. Although it is probably impossible to completely disentangle the effects of the process of being involved and the effects of the actual decisions made, a number of studies point to there being an independent benefit from involvement, through reduced decisional conflict (O'Connor et al. 1999) and enhanced sense of control (Street and Voigt 1997, Gattellari et al. 2001). A key finding from Gattellari and colleagues is that patients' perceived role in decision-making independently predicted satisfaction, irrespective of their stated preference for decision-making style. Discrepancies between perceived and preferred roles had an independent but temporary effect on anxiety, but had no independent effect on satisfaction with the consultation or with information and emotion support received.

It is possible for these forms of benefit to compete, as when patients presenting with viral symptoms ask for prescriptions for antibiotics (Gwyn and Elwyn 1999).<sup>1</sup> Clinicians attempting to practice shared decision-making in such situations can find such interaction difficult to manage. Gwyn and Elwyn (1999) suggest that the problem in this example is lack of equipoise (a situation in which there is enough uncertainty about what is best that “options really are options”). These authors (Elwyn, Edwards and Kinnersley 1999) report that many registrars say they “choose the data to help the patient make the decision you think they ought to make”, and feel that decisions should be shared only when there is equipoise. One of the problems with this approach is that the doctor’s authority to identify the best interests of the patient is assumed; and the doctor is concerned about public health interests when the patient often is not (Brock and Wartman 1990). The question of exactly who gets to pronounce something an instance of equipoise, and on what basis, is a complex and contentious one (see for example Lilford 2001), but ultimately it must be seen as a consensus of some kind, interactively and discursively produced. If we want to examine the role of equipoise in shared decision-making, we need to treat it as a product of the institutional discourse of medicine.

Like equipoise, notions such as ‘eligibility’ (*of the patient for the trial*) versus ‘suitability’ (*of the treatment for the patient*) need to be acknowledged as indexing discourses which may conflict with each other. Central to this potential conflict is the way in which different assumptions about agency are built into the different discourses. Assumptions about who is in a position to speak about what are built into the routine practices of medicine through its discourse. Even the idea that health care ‘produces’ benefits, or outcomes, must be considered part of a particular medical-organisational discourse (Iedema 2002). Many assumptions, such as that the doctor knows and acts and the patient complies and benefits, are inherited in the literature on shared decision-making, despite its critique of paternalistic medicine. I am flagging two things here. One is a need to interpret the social process of shared decision-making from a

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<sup>1</sup> Such scenarios become quite complex because doctors sometimes prescribe on the basis of what they expect patients ‘prescription hopes’ are (Britten & Okoumounne 1997), and because clinical guidelines do not always reflect strong consensus – eg doctors in the US prescribe antibiotics for what they call ‘strep throat’ but in the UK there is no such condition.

discourse perspective. The other is that taking a discourse perspective emphasises the role of agency, and its representation and transformation, as a critical variable in the debate about decision-making style. I will pick these points up throughout the chapter.

### **2.3.2 Preferences and practices**

Key findings on preferences and practices are summarised in Table 2.2. The details of this picture are complex. Patients can be ambivalent between asserting themselves 'in a consumerist manner' and taking a 'passive role' (Lupton 1997), or can have different preferences at different times, particularly when their illness becomes more severe (Butow et al. 1997). Some authors argue that preference approaches are limited because they are based on hypothetical choices, and are difficult to predict, both by the theorist and by the clinician (Elwyn, Edwards and Kinnersley 1999). In discussing this issue, Kravitz and Melnikow (2001) maintain that despite different preferences:

...a desire for information is nearly universal. Most patients want to see the road map, including alternative routes, even if they don't want to take over the wheel.

Most of those who study this area would have no disagreement with a statement about preferences couched in such metaphorical terms, but there are very different views about how this translates into practice. It is therefore useful to look at some of the preference studies in detail.

A seminal empirical study, entitled 'Do patients want to participate in medical decision-making?', (Strull et al. 1984) modelled patient participation according to the following 'stages' of the decision process:

- i) disclosure of information;
- ii) discussion of therapeutic alternatives; and
- iii) the 'actual decision making'.

The main, much-cited, finding of this study was that clinicians underestimated patients' desire for information and discussion, but overestimated patients' desire to make decisions. It should be added that many patients who did not want to make initial therapeutic decisions did want to participate in ongoing evaluation of therapy.

It is interesting that this study did not consider how much information *clinicians* got from their patients, and how this compared with how much they wanted, indicating an assumption by the authors that clinicians have privileged access to all of the information that could be useful to decision-making. The sort of information that was omitted includes patients' information about their health beliefs, daily routine, eating habits and drug reactions. Strull et al. found that clinicians were much more likely to underestimate the amount of discussion each patient wanted than to overestimate it. Clinicians thought that older, less well-educated, non-white patients, and those being treated in the community hospital clinic, would want less discussion; in fact those in the community hospital clinic, along with those in a Health Maintenance Organisation, wanted more discussion on average, as did those with more severe illness, although the clinicians were right about the less well-educated patients, who wanted less discussion (in this particular study). Regarding "actual decision making", physicians overestimated how much the patient thought he or she was participating in his or her treatment decisions in 48% of cases, and underestimated it in only 6% of cases. Taken together with the results about information disclosure, it seems that patients very often believe they are being well-informed but also believe the clinician makes the decision unilaterally, whereas doctors more often think they are giving out less than maximum information but are taking patients' opinions into account. One possible explanation for these discrepancies is that clinicians and patients both recall the same dialogue, but what patients think of as "getting information" doctors think of as "patient participation" or at least "considering patients' views". It is hard to reconcile this interpretation with the implication in the design of the study that information is given only from doctor to patient.

Despite the lack of data, an interesting alternative analysis can be done in a rough sort of way by comparing the difference between patient preferences and perceived current practice with the difference between clinician preference and perceived current practice. On the whole, clinicians' views of what was happening were very similar to their view of what *ought* to happen: 20% reported unilateral clinician decisions being the norm, while 22% would like to make unilateral decisions. (We do not know how much overlap there was between those two groups, but it seems likely that there was a lot.) Among patients, 63% thought clinicians usually made decisions unilaterally, compared with 47% who thought that *should* be the case. The discrepancy is marked.

Another much-cited paper in this area, (Braddock et al. 1997), reviewed literature on patient participation in decision-making and informed consent. They maintain that decisions in medical treatment should comprise informed consent, which itself ideally comprises the following characteristics (not necessarily in sequence):

- i. description of the nature of the decision
- ii. discussion of alternatives
- iii. discussion of risks and benefits
- iv. discussion of related uncertainties
- v. assessment of the patient's understanding
- vi. elicitation of the patient's preference

Of 262 occasions of decision-making in the study, none of the decisions contained all six of the recommended elements, and only 0.4% contained as many as 5 of them. 15% had none of the elements at all, and 15% only had one element. Physicians frequently described the nature of the decision, less frequently elicited patient's preferences, rarely discussed the risks and benefits of the treatment proposed, and only very rarely assessed patient understanding of the decision or talked about uncertainty. The authors concluded that discussions leading to clinical decisions in these primary care settings did not fulfil criteria considered integral to informed decision-making (although they acknowledge that it is probably not necessary for all clinical decisions to contain each of these elements). They suggest that applying the traditional concept of informed consent could result in missed opportunities to involve patients in the entire range of



important clinical decisions in office practice. A less diplomatic way of saying this would be that if doctors think they are conforming to requirements for patient participation by getting written consent, they're probably wrong.

Braddock et al. suggest that many doctors and commentators dismiss calls for participatory decision making because doctors are too busy, even though (as they admit) it is not clear that informed decision-making takes a long time, and Butow and her colleagues have shown that in some circumstances increasing patient participation can reduce consultation time (Brown et al. 2001). Cassell (1985) makes a similar point when he shows how allowing the patient to finish their account, in their own words, of why they have come for consultation can save time when compared with the more traditional interview method of 'history taking'. More recently, Ainsworth-Vaughn (1998) argues, for similar reasons, that doctors should allow patients to tell their own narratives even if they seem anomalous.

Other studies have also found that doctors often fail to talk about the risks and benefits of proposed treatment. In a study comparing physician-self-reported disclosure of risks and benefits with patient-reported physician-disclosure, doctors claimed to have explained potential side-effects in 93% of consultations, whereas patients reported receiving such information only 69% of the time (Louis Harris and Associates 1983, cited in Braddock et al. 1997). Sulmasy and colleagues (Sulmasy et al. 1994) found physician disclosure of information to patients undergoing routine medical procedures ranged from 90% for explaining the procedure itself to 53% for explaining the alternatives. Wu and Pearlman (1988) found a similar preference in doctors for explaining the procedure they were about to do more frequently than alternatives, risks, and benefits. Note again that the researchers' conception is one of information provided *by* the clinician *to* the patient: no results are reported on whether patients say anything about risks or benefits or alternative treatments.

A somewhat different approach can be seen in the contribution of the anthropologist Robert Hahn (1983) to the US President's Commission for the Study of Ethical Problems in Medicine and Biomedical and Behavioral Research. Hahn draws out to the more general aspects of patient participation in decisions, and extends the focus of enquiry from the behaviour of the doctor to what he calls a 'reciprocal

exchange' between doctor and patient. He examines informed consent as an act of 'intercultural communication', where differences in culture may include tensions between mainstream American culture and American medical culture.

Donovan and Blake (1992) appear to conceive of treatment decision-making as a two-stage process consisting of quite different and distinct roles and stages:

- i) the doctor informs
- ii) then the patient decides.

In this study, patients were found to be more compliant with certain types of medications (so-called 'second line' arthritis medications, as opposed to the primary treatment for arthritis, non-steroidal anti-inflammatory drugs). Donovan and Blake argue that this was because doctors gave them more information about second line drugs than about first line drugs, including a rationale for using them. Patients were "able to understand and recall this information, and then decide whether or not to participate" (Donovan and Blake 1992: 509) but this increase in information and understanding appeared to lead some patients to decide not to go on the recommended therapy.

Where other authors would describe this finding in terms of patients making irrational choices (e.g., Brock and Wartman 1990), this behaviour is characterised by Donovan and Blake (1992) as rational action on the part of the patients. The patient conducts a type of cost-benefit analysis with all the information available, and continues to calculate the costs and benefits outside the clinic after their consultation. Presumably doctors also carry out a kind of cost-benefit analysis before recommending treatment, but in Donovan and Blake's model there does not seem to be room for a joint, interactive cost-benefit analysis carried out by doctor and patient together. Given that patients often remake the treatment decision by not complying with treatment after it has been prescribed, doctors' assessments of the cost-benefit ratio may be different from patients' assessments, indicating that doctors could benefit from dialogue with patients at the time of their analysis. Donovan and Blake anticipate this when they argue that "perhaps the issue now should not be compliance, but how medical staff can understand and participate in the decisions that patients already take about their medications!"

Such a suggestion has recently been echoed by Benson and Britten (2002), who write that “doctors who want their patients to make well informed choices ... should explore how individuals strike this balance, to personalise discussion of drug use.” This recognises the fact that patients have their own knowledge and expertise that they *bring* to the consultation, although it should be stressed that such expertise may need to be actively and interactively brought out and capitalised on in the interaction.

Evidence from the compliance/adherence/ concordance literature also reminds us that ‘balancing’ reservations about treatment against positive construals of treatment makes the ‘treatment decision’ an ongoing process that the patient must revisit daily. This is an aspect of practice – and the debate about practice – where agency is central.

### **2.3.3 Viewing medical interactions as jointly achieved**

In the model of doctor-patient interaction represented by the patient preferences literature cited above, we can observe a weak version of the idea that doctors and patients jointly produce a decision style. This is seen in the idea that patients have specific preferences which they have to tell the doctor early in the consultation, or which the doctor needs to find out by some other means. A much stronger version of the idea of jointly produced interaction styles – and, by implication, decision-making styles – is presented in the work of Maynard (Maynard 1991, cf. Heath 1992, ten Have 1991).

Maynard (1991) argued against the prevailing view that medical consultations merely display an inherent social asymmetry, in which medical authority is imposed by powerful doctor onto a less powerful patient. Maynard showed that, rather than being imposed, asymmetry is actively achieved in situ by doctors and patients. This is possible because doctor-patient interaction involves sequences of talk, such as the Perspective Display Series in breaking bad news, which have their home in “ordinary talk” (Goffman 1972, Cicourel 1973). Such sequences function as ways of displaying mutuality of perspective but may be used to achieve clinical authority by ‘embedding’ the patient’s position within the clinician’s view. This idea will be taken up in later chapters discussing agency and alignment. Both Maynard and Heath found that attempts to elicit patients’ contributions often serve to maintain the contrasting status of the doctors’ and patients’ roles (cf. Aronsson and Sätterlund-Larsson 1987). More

recently, Gwyn and Elwyn (1999) have raised a similar concern. They describe a case in which a doctor attempted to engage the patient's parents (the patient was a small child) in shared decision-making about antibiotic treatment, only to have the parents treat these questions as rhetorical.

An earlier study which treats doctor-patient consultations as interactively achieved, but which also attributes a good deal of the asymmetry observed in doctor-patient interaction studies to the tools used for its observation, is Mishler (1984). Mishler drew strong lines between what he called "mainstream research" and "alternative methods". The former distorted the object of study by being insensitive to communicative details of speech such as false starts and repetition, and were constructed with built-in medical bias – for instance observing only doctors' utterances not patients' (e.g., Byrne and Long 1976), or in other ways interpreting the social action of the interaction asymmetrically in terms of what the doctor (therapist) "is trying to do" (citing Labov and Fanshel 1977). Mishler also describes a conflict between the "voice of the lifeworld" and the "voice of medicine" (cf. Habermas 1984). The "voice of medicine" is described as having a particular sequential structure (Question–Answer–Evaluation/ Assessment), and is criticised as dominating the voice of the lifeworld, which is the "experiential province of the patient".

Mishler acknowledges that it is possible for physician and patient to speak in either voice, but his work is pervaded by a serious conflation of concepts in which "voice" is equivalent to both embodied social subject and to meaning potential. Additionally, and equally problematically, Mishler represents the investigator's options as dichotomous, the biomedical perspective of physicians or the lifeworld perspective of patients. From the point of view of explaining – and possibly resolving – such conflicts, it would be best to determine the number and type of perspectives from evidence in the text, as well as from a more macro understanding of the institutional, professional and personal contexts of consultations under scrutiny. The investigator is in a position, with a suitable theory of language, to describe this variety of perspectives; to account for what makes them count as different perspectives for the speakers concerned and for the broader audience of practitioners or investigators; and to show how interactants negotiate their way through different perspectives, rather than restricting themselves to

Mishler's two predetermined choices of perspective. Another problem with Mishler's analysis is that it fails to recognise that people go to the doctor to access highly developed expertise. This expertise has its 'contextualised understandings' just like lifeworld expertise and experience. The voice of medicine could be considered a valuable resource for the voice of the lifeworld to appropriately negotiate with, rather than something to move beyond. By packaging together medically oriented representations of events, power relations between doctors and patients, and the assumption (not necessarily borne out by observation) that it is doctors who speak in the voice of medicine and patients who speak in the voice of the lifeworld, Mishler has made it difficult for a valid (as opposed to legitimate) and socially conscientious voice of medicine to be encouraged, described, recognised, ratified.

Despite these criticisms, Mishler's (1984: 20) call for "methods which were more respectful of the structure and meaning of spoken discourse" is still highly relevant. There have been a number of positive developments, such as Fallowfield and colleagues' elaboration of the Interaction Process Analysis method (Roter 1991) in a way which recognises the multidimensional character of interaction (Ford et al. 2000). This method allows both sequential and parallel coding – i.e., the researcher can allocate more than one category to one 'unit' of interaction. However, such models still lack ways of systematically relating the coded 'verbal behaviours' to each other in important ways – e.g., we want to be able to consider moves in order of abstraction that hold between manifest tokens such as *exactly* and *mm-hmm* and what they are taken to 'mean', e.g., agreement and understanding.

Putting the patient back in the picture from a somewhat different approach, a recent volume by Ainsworth-Vaughn (1998) reports that patients asked 40% of all questions in her observational study. This figure compares with figures of 1% and 9% in other studies (Frankel 1979, West 1984). Patients were also shown as being able to work with aspects of doctor-patient interaction typically considered as features of asymmetry, such as rhetorical questions, to achieve their own ends. These claims are evidence of a high degree of agency among the patients observed (oncology patients), in terms of what Ainsworth-Vaughn describes as patients being able to 'implement their own agenda'. Ainsworth-Vaughn also presents analysis showing that patients initiate topic

changes, but are much more likely to change topic where this was a 'reciprocal decision' rather than a unilaterally imposed change of topic.

Studies such as Mishler (1984), Maynard (1991) and Heath (1992) can be considered to be making the claim that interactions are jointly constructed even when the co-constructors are at odds, or have different points of view. Such a view is also implied in socially oriented theories of language (e.g., Halliday 1973). Such a view implies a number of things:

- i) Both doctors and patients are epistemic and semiotic agents.
- ii) The process of doctor-patient consultation is not predominantly a process of information transfer, but of meaning-making across broad functions of language and in relation to the specific purposes of each interaction.
- iii) The doctor and the patient are not interacting in a social vacuum (Gwyn and Elwyn 1999). They are engaged in particular professional and institutional practices, and simultaneously in an instance of social interaction more generally. These are shaped by what Sarangi and Roberts (1999) call the interaction order (Goffman 1974) and the institutional order (Berger and Luckmann 1967, cf. Foucault 1984).
- iv) These *orders of discourse* in turn can be seen to draw on different *discourses*, including discourses that transcend any particular professional discourse, and especially discourses of health measurement, health care, and health experience.
- v) Doctors and patients will usually have different perspectives which can best be understood as different orientations to these discourses, rather than as permanent association with one or another. In order to reach what Benson and Britten (2002) call "concordant decisions", doctors and patients need to negotiate between these different discourses.
- vi) Although there may be only two people in the consulting room making the decision, the perspectives, discourse orientations and power of other agents – both individuals (partners, lovers, family members, respected colleagues, consultants) and those who are not individual human agents (the HIV community press, treatment information leaflets, websites, the medical literature, conference recommendations, clinical guidelines, budget requirements, etc) are present as perspectives that need to be taken into account as well. This recalls Geertz's 'webs of significance' (Geertz 1973),

and Goffman's notion of a backstage/ frontstage dichotomy in public life (Goffman 1969/ 1959).

In an overview of research on workplace interaction, Sarangi and Roberts (1999) claim that sociolinguistic research, including research on medical interaction, has tended to focus on the interaction order at the expense of the institutional order, that sociological studies have tended to go to the opposite extreme, and that few studies have been able to show how the two orders overlap to explain phenomena such as decision-making processes (cf. Pappas 1990 – see below). A number of other oppositions are raised in the article which Sarangi and Roberts call on researchers to bring together, including Goffman's backstage and frontstage dichotomy. Sarangi and Roberts remind readers that decision-making processes are discursively dispersed and fragmented (Atkinson 1999, 1995, Boden 1994). The view that decision-making is inherently ephemeral does not appear to sit well with a view of shared decision-making in medicine as a set of steps or competencies.

There is a clear need to clarify shared decision-making using an approach which can relate a view of decisions as institutional and professional practice, to a view of decisions as interactions between social actors, which unfold in real time through turns at talk that are contingent on each other, and for which the medium is natural language (in the case of the present study, English). The way in which these two perspectives are related is summed up succinctly by Linell: in instances of interaction, "views collide and coalesce. What is being exchanged is not only words and discourses, but the worlds that make discourse" (Linell 1998: 149). At the same time, it is words (or wordings) that make these exchanges of discourses and worlds real. As Halliday insists, "the powerhouse of a language is its grammar" therefore "observing the grammar at work helps to provide some of the perspective that critical discourse demands" (Halliday 1998: 2).

A recent paper by Skelton et al. (Skelton et al. 2002) goes some way towards taking the approach I am recommending. It is an interesting (and rare) example of a corpus analysis of specific linguistic choices made by doctors and patients, as a way into describing how participation is realized in practice. Skelton et al. studied 373 primary care consultations, examining pronoun use, and verb collocations with pronoun

choices. They found that doctors used “we” more frequently than patients (24% cf. 3% of all personal pronoun occurrences respectively). Doctors were far less likely to use “I”, and when they did so it was usually with a verb of *thinking*. Skelton et al. argue that “the fact that patients and companions never included the doctor when they said ‘we’ is particularly interesting and – from the point of view of patient partnership – disappointing.” They conclude that doctors’ patterns of pronoun use show “a systematic ambiguity at the heart of the consultation, which at worst may permit doctors to feel they are inclusive when in fact they are not.”

While it is encouraging to see corpus approaches to studying participation styles in medicine, I would argue that this study treats pronoun selection almost as a free-floating index of symmetry in interactions. But clearly pronoun use is not a good index of symmetry on its own. (If doctors and patients had used “we” in the same proportions, would the authors have interpreted this as evidence of complete symmetry?) Pronoun choices in conjunction with verb selections appear to be important for Skelton et al. as a way in which interactants represent and deploy agency, but it is assumed that patient agency should be maximised, regardless of patient preference, phase of the consultation and so on. It is also assumed that a use of ‘professional we’, as in “we know now that there is no latency period in HIV”, is just as much a token of asymmetry as “we don’t want you to lose even more T-cells”. A number of theoretical and methodological steps are required to properly flesh out the relationship between pronoun selection and its meaning in the context of a particular phase of a particular interaction. This points to the need for linguistic studies to be firmly grounded in an understanding of professional and institutional discourse, and in an understanding of grammar and semantics, preferably a functional grammar that can relate discourse as ‘talk’ to discourse as ‘practice’.

#### **2.3.4 Decision-making and interaction styles in HIV medicine**

Joint decision-making has been a critical issue in HIV medicine for many of the same reasons as in other fields. In HIV medicine, however, the clinical and political stakes are simultaneously amplified. In affluent countries such as Australia, appropriate treatment may lead to years or decades of extra life. But appropriate treatment is difficult. Current



combination therapies (HAART) are the most complex regimens that have ever been prescribed for continuous open-ended treatment of *any* disease (Chesney et al. 2000). Side effects from taking the drugs exactly as prescribed can be persistent (diarrhoea, nausea) or permanent (lipodystrophy, and liver and nerve damage) and are often the first experience of feeling unwell in otherwise asymptomatic HIV-positive (HIV+) patients. Drug resistance develops easily, and treatment effects drop off markedly, when patients drop below an extremely high threshold of adherence to their drug regimens (at least 80% according to Chesney et al. 2000, and some say as high as 95%). Social and psychological costs are also significant and common, including the excessive governance of HIV+ people's day-to-day lives (Race et al. 2001), in particular the medicalising of their sex lives (Rosengarten et al. 2000). These factors can all be exacerbated by insensitive treatment decision-making. Access to HAART, and therefore the stakes of choosing and implementing treatments, are still largely confined to affluent countries, but this is changing, and the issues discussed in this study are becoming increasingly relevant for less developed countries (Swartz and Dick 2002).

HIV communities have to some extent revisited the "same old problem" (Wright 2000) of adherence to doctor's recommendations, but they have also extended and shifted the debate towards an more empathic approach (Squier 1990) which focuses on relationships rather than on the sorts of individual patient characteristics which tend to be construed as deviance or irrationality (Moatti and Souteyrand 2000, Lerner et al. 1998). Lerner et al. argue that doctors should encourage *all* HIV+ patients to devise individualised treatment plans that can facilitate reliable ingestion of medication. This is quite a distinct approach from that of attempting to predict those who are likely to be nonadherent (non-compliers) and targeting them with a specific "intervention" to "remove barriers to adherence", as if these could be got out of the way, when research suggests that non-adherence is dynamic: it can happen from time to time for various reasons, for any patient (Moatti and Souteyrand 2000, Spire et al. 2002).

Research on doctor-patient interaction in HIV medicine has included qualitative studies of interviews and consultations that take a more discursive approach, as well as standard quantitative surveys.

As table 2 suggests, HIV treatment decisions tend to be more participatory than in other medical fields, at least in affluent countries. In a national review of treatments, services and health among HIV+ people in Australia, most participants reported having a co-operative relationship with their doctor, with joint decision-making being a common aspect of the relationship (Prestage 2001: 58). This report also showed that the doctor's recommendation is by far the most important influence on the decision to take antiretroviral combination therapy. These results (especially when taken together with my own data) seem to describe a patient population that expects and experiences a higher level of participation in their own treatment decisions than the groups with hypertension and arthritis reviewed above. I take these findings to indicate that patients can consider their experience of decision-making as maximally shared, while at the same time their doctor's recommendation can be the most important factor influencing a decision, without any contradiction between the two. This claim problematises the use of a ranked or scaled instrument for eliciting preferences (Degner et al. 1997). Also, the distribution of people's responses to slightly differently phrased questions in Prestage et al. (2001) suggests that giving them a 'forced choice' question about degree of participation is unlikely to reflect the way participants understand the context. Certainly, forcing a choice between "I prefer to make the final selection about which treatment I receive" and "I prefer to make the final selection of my treatment after seriously considering my doctor's opinion" is going to yield misleading and unreliable results, since it is an attempt to make a scalar distinction out of an elaboration.

A recent focus group study (Marelich et al. 2002) supports these positive views, finding that "HIV/AIDS patients were generally active in making treatment decisions with their providers, garnering information about antiretroviral treatments from a variety of sources including peers, family members, health professionals and the media" (cf. Natarajan 2002). Paralleling the difference in degree of shared decision-making between the disease communities, HIV appears to have a particularly high rate of treatment adherence. A recent study (Walsh et al. 2001) found that median self-reported adherence was 95% (n = 178, range = 60-100%). This compares with approximately 50-60% for other diseases (Haynes and Dantes 1987) although some

studies of adherence in HIV have found adherence to be more in line with rates in for other diseases.

These themes have been part of the discourse of HIV medical practice for some time (Stewart 1997). The implementation of a participatory ethos has been encouraged and critiqued within HIV peer education and social research. Despite the lack of studies of the effect of decision-making style on adherence or outcomes in HIV, together these studies mount an 'ecological argument' for a relationship between participation style and adherence in this population of some weight.

This relationship is not without clinical problems or methodological problems, however. Studies have reported that increasing patient participation in decision-making reduces treatment uptake, compared with clinical guidelines or decision analysis (Montgomery and Fahey 2001, Protheroe et al. 2000). Race et al. (1997) reported that uptake of appropriate antiretroviral treatment (HAART) appeared to be compromised, compared to the extensive use and acceptance of complementary therapies by people with HIV (cf. Walsh et al. 2001). Race et al. identified the adoption of a 'sick' identity as one of the key barriers to taking allopathic medicine. Rather than treating this barrier as a result of a psychological state of denial, they argued that meanings around complementary medicine foregrounded "maintaining health". Meanings around HAART, on the other hand, foregrounded "treating HIV" in a way which made it difficult to represent antiviral treatments as enabling, and difficult to incorporate them into a positive outlook on the future and patient's day to day lives. Two of their conclusions are central motivations for the present study. Firstly, they suggest that cultivating agency or capacity with respect to health practices among people with HIV is vital. Secondly, the ways in which the person with HIV is positioned in the clinical encounter (whether agentive or passive) may affect their capacity to make informed treatment decisions and to sustain and manage combination therapy.

Race et al. use their findings to question the desirability of shifting the burden of responsibility for decision-making from doctor to patient, bearing in mind the complex and often inaccessible nature of medical knowledge. Notwithstanding the catch-cry of treatment activist groups to 'get informed', they argue that the consumerist model of health care is not the solution to the problems they have raised. They suggest that the

shift in the representation of health agency may be more important and ethically desirable than a complete transfer of responsibility, and they therefore recommend further research on the negotiation of health agency within the clinic (Race et al. 1997: 12). This suggestion relates directly to the work presented in chapters 4 and 6.

In follow-up research on “adherence and communication”, Race et al. (2001) suggest moving from a discourse of compliance, or adherence, or concordance, to developing a “patient expertise on living with treatment”. This “is meant to register a more critical and active engagement with the discourses of health and medicine necessary to overall wellbeing, 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”. It is useful not just for promoting compliance but also for thinking about how to support people for whom treatment is failing. (Note that they avoid speaking of patients who have failed their treatment.)

Another reversal recommended by Race et al. is that the patient’s world should no longer be constructed as the “impediment that the doctor corrects”, but becomes the essential reference point in the technical formation of ‘problems’ and ‘solutions’. In a companion study (McInnes et al. 2001); Race and colleagues argue that it is the way in which the medical-scientific and lifeworld knowledges are brought together in consultations that is crucial. If the medical knowledge is continually used as the experiential domain for expanding on patients’ contributions (e.g., by “correcting” a lay term with a technical one), this has the effect of foreclosing on shared construals and shared decisions. This argument shares similarities with the arguments of Donovan and Blake (1992), RPSGB (1997) and Benson and Britten (2002) for personalised decisions, but makes a more explicit appeal to the collaborative effort required by both doctor and patient. It also picks up on Mishler’s ideas as discussed above. But, importantly, Race et al.’s proposal requires doctors and patients to be able to move more in both ‘worlds’ whereas for Mishler the lifeworld is the province of the patient – hence the conflation of field and identity in his choice of term ‘voice’.

In a focus group study of quality of life and HIV in Hong Kong, Jones et al. (2000) found that the biggest communication problems between people living with HIV and health care workers revolved around discussing medications and adherence.

Treatment tended to be framed in terms of individual choice or responsibility rather than social activity, and adherence was framed in terms of patients' "ability to 'learn' and 'understand' the instructions of health care workers" (Jones et al. 2000: 39). Jones et al. concluded that despite avowed commitments to patient choice and shared expertise, both groups talked about their experience in terms of 'compliance' and 'ability' rather than as matter of shared goals and decision-making. The authors interpret this as only partially a matter of deference to authority figures characteristic of Chinese culture, arguing that the problem exists more universally in HIV care. They cite Mouton et al. (1997), who found that only 35% of their HIV+ respondents in their US study reported discussing treatment preferences with their doctors, and that those with the lowest education and income were least likely to express preferences.

Arguably, though, the experience of HIV+ people and their doctors in managing combination therapy has already profoundly challenged paternalistic decision-making practices (Moatti and Souteyrand 2000), even if it has not changed those practices universally; and it has certainly influenced clinical research agendas and the regulatory environment in which these are embedded (Aggleton et al. 1997, Epstein 2000). There is some evidence of an 'interactive turn' in the way that health care is practised and theorised, but the evidence is mixed, and there are still strong inherent tensions between approaches. Fundamental to this tension is a persistence in treating the doctor's communicative behaviour as an independent variable, and patient's behaviour as a dependent variable, or vice versa, and sometimes both. In the next section I will elaborate on current models of medical decision-making, in order to pave the way for a more multi-dimensional approach.



**Table 2.1: Findings about the effects of joint decision-making & related aspects of consultation style**

<i>Authors</i>	<i>Year</i>	<i>Variables</i>	<i>Findings</i>	<i>Comments</i>
Haynes and Dantes	1987	Adherence (background)	50-65 % of patients with chronic conditions adhere to treatment	Findings in HIV populations tend to be higher
Prestage et al.	2001	Adherence to HAART type of problem	20% missed doses every week 25% had missed in the 2 days prior to study 90% had missed at least once in 12 months	Respondents who missed doses every week considered it very important to take their pills as prescribed, and most believed that missing doses was a serious matter that could affect their health
Walsh et al,	2001	Adherence to HAART Reasons for non adherence	95% median adherence among HIV+ population to HAART	
Gattellari et al.	2001	Patient perceived SDM ↑ satisfaction Role mismatch	Patients who felt they had shared decisions were more satisfied; patients with role preference and perceived role discrepancies were more anxious	Perceived role in decision making as shared was associated with positive benefits irrespective of patient's stated preference for higher or lower participation.
Montgomery et al.	2001	clinician's provision of info ↓ treatment uptake	Patients with mild-moderate hypertension rated benefits of medication lower and rated distress of side effects as higher than doctors (esp. specialists)	Authors suggest that shared decision-making will sometimes lead to adverse outcomes – undermedication, excess morbidity etc.
Edwards et al.	2001	clinician's provision of info ↓treatment uptake (general practice)	Providing more information (or more understandable information) is associated with improved patient knowledge and a greater wariness to take treatments or participate in trials.	Important findings which imply the need to clarify terms such as <i>loss framing</i> and <i>complex vs simple</i> information, <i>more versus less information</i> . If measure the "effects" of these phenomena as "variables", can we ever "control" other sources of bias in the meanings exchanged?
Kaplan et al.	1989	ratio of talk (P:D) ↑ health outcomes (diabetes)	Increased ratio of patient:doctor talk was related to better overall health ratings, reduced number of days lost from work, and fewer functional limitations	(Kravitz & Melnikow 2001) interpret these results as "evidence that expanding the involvement of patients in care produces better health outcomes, providing an empirical rationale for what may have been an inevitable shift in power"
Orth et al.	1987	patients using own words ↑ health outcomes (hypertension)	hypertensive patients who talked about their concerns in their own words, rather than answering closed-ended questions, were more likely to have lower blood pressures	

**Table 2.1: Findings about the effects of joint decision-making & related aspects of consultation style**

<i>Authors</i>	<i>Year</i>	<i>Variables</i>	<i>Findings</i>	<i>Comments</i>
Davenport et al.	1987	highly structured clinician interactive style ↓ symptom disclosure	clinicians' basic interviewing techniques, eg, avoiding eye contact and asking many closed questions about physical symptoms discourage patients disclosing details concerning their psychological state.	
Roter and Ewart	1992	patient psychosocial focus ↓ doctor psychosocial focus ↓ diagnosis of distress  Is there an independent/dependent variable model here? <sup>1</sup>	Physicians underestimated the amount of emotional distress suffered by hypertensive patients in comparison with a control group. Content analysis showed that the hypertensive patients were asked fewer psychosocial questions, engaged in slightly less psychosocial talk and significantly more biomedical talk than controls.	Patients have effects on consultation process and outcomes, they are not merely reactive to doctor styles.
Maguire et al.	1996	highly structured clinician interactive style ↓ patient disclosure of concerns	Disclosure of concerns was promoted by: (a) the use of open directive questions, (b) focusing on and clarifying psychological aspects, (c) empathic statements, (d) summarising and (e) making educated guesses. Inhibitory behaviours included the use of leading questions, focusing on and clarifying physical aspects and moving into advice and reassurance mode before patients' problems had been fully explored	The features described as promoting patients' disclosure of concerns could be glossed as using 'patient centred' communication. They can also be construed as more conversational, more symmetrical, and elastic in terms of phase
Stewart	1984	clinician interaction style ↑ patient participation in consultation	Employing a patient-centred approach can encourage patient participation in the consultation. The patient-centred encounter is one in which the clinician behaves in a manner that facilitates patient expression so that he or she feels free to speak openly and ask questions	

<sup>1</sup> Note that these studies mostly construe patient behaviour as dependently responding to doctors' independent behaviour.



**Table 2.2: Findings about patient and doctor preferences for participation in treatment decisions**

<i>Authors</i>	<i>Year</i>	<i>Study type</i>	<i>Variables</i>	<i>Findings</i>	<i>Comments</i>
Prestage et al.	2001	Community survey of HIV+ respondents n= 451	Relationship with doctor in making decisions about treatment (practice not preference)	<ul style="list-style-type: none"> <li>• Most patients reported a co-operative relationship with their main doctor.</li> <li>• 30 % said "I tell Dr what I want"</li> <li>• 60 % said "doctor and I" make decisions together</li> <li>• 20% said Dr makes the decision</li> <li>• 10 % said they were somewhat pressured by their Dr</li> </ul>	<p>Percentages don't add since multiple responses were allowed.</p> <p>Preferences were not asked, but 70% were very satisfied and a further 15% were moderately satisfied with their medical support.</p>
Degner et al.	1997	Survey of women with breast cancer n= 1012	Preference	<ul style="list-style-type: none"> <li>• 22% wanted to select own Rx</li> <li>• 44 % want to collaborate with doctors on decision</li> <li>• 34% wanted to delegate decision</li> </ul>	
Strull et al.	1984	Patient & clinician questionnaire	<ul style="list-style-type: none"> <li>• Patient &amp; clinician reported practice</li> <li>• Patient &amp; clinician preferences</li> </ul>	<ul style="list-style-type: none"> <li>• Most patients want maximum information and discussion</li> <li>• Most patients preferred clinician to make decisions</li> <li>• Clinicians underestimate patient information and discussion needs</li> <li>• Clinicians over estimated patients preferred level of participation in decisions</li> </ul>	<ul style="list-style-type: none"> <li>• Results not highlighted include more patients than clinicians wanted greater patient participation than they perceived was current practice.</li> <li>• Patient and clinician definitions of what is information and what is participation in decision-making may be different</li> <li>• Patient and clinician definitions of what is a lot of discussion or a lot of information may also differ.</li> </ul>
Butow et al.	1995	Computer interaction analysis of transcript		<ul style="list-style-type: none"> <li>• oncologist behaviour varied significantly according to the</li> </ul>	

**Table 2.2: Findings about patient and doctor preferences for participation in treatment decisions**

		n=1 oncologist		age, sex and involvement preferences of patients	
Butow et al.	1997	Patient questionnaire	Preference stability over time	<ul style="list-style-type: none"> <li>• Patients whose condition had worsened wanted to decrease their involvement in decision-making.</li> </ul>	
Gattellari et al.	2001	Patient questionnaire; videotaped	Patient preference for decision-making role (after Degner)	104 patients wanted to share 57 wanted mostly D to decide 49 wanted mostly P to decide 29 wanted D only 2 wanted P only	
Skelton et al.	2002	Lexical concordance study of 373 consultations (audio taped data)	pronoun use by role  verb collocations with pronouns	Doctors used "we" more than patients: (23.5% cf. 2.9% of all personal pronoun occurrences)  Doctors are far less likely to use 'I', after which a  verb of <i>thinking</i> is usually selected.	Skelton et al. treat pronoun use as an indicator of participation and symmetry. The findings suggest a prototypical pattern of interaction in primary care: Patient: I suffer. Doctor: I think. They see this as evidence that power relationships in the consultation may still be unequal.

2.4 Models of decision-making

In this section I want to identify some of the conceptual issues which motivate the approach taken in this thesis. I will distinguish between two related but distinct questions: *How has medical decision-making, as an activity, been modelled?* and *How has variation in styles of decision-making (paternal, shared etc.) been modelled?* My argument will be that, by and large, medical decision-making as an *activity* or *social process* has only been modelled dynamically, whereas *variation* in decision-making style has been modelled synoptically. This makes it difficult to integrate our descriptions of what shared decision-making is like, and how it is different from other forms of medical decision-making. I will expand on these two questions below, in reverse order, and in Chapter 5 I will provide an integrated synoptic and dynamic description on the basis of my own data.

2.4.1 Modelling *variation* in decision-making style

Discussions of shared decision-making tend to present it as the middle ground between two extremes. In their recent review article, for example, Elwyn, Edwards and Kinnersley (1999) summarise the main models of doctor-patient decision-making as constituting a “spectrum from a paternalistic model at one end, to the informed choice model at the other end”, citing Byrne and Long (1976) and Charles et al. (1997). “In between these” they say “is the model of shared decision-making” (Elwyn, Edwards and Kinnersley 1999: 477).



Figure 2.1 Decision-making styles as spectrum (after Elwyn, Edwards and Kinnersley 1999, Charles et al. 1997)

Robinson and Thomson (2001: i35) fill out this view by saying that the paternalistic style “assumes primacy for the doctor’s clinical knowledge and makes no (or little) concessions

to patients' preferences" and that the "informed consent" end of the spectrum, in its purest form, "assumes the patient alone will make the treatment decision once he (sic) has been given all necessary clinical information". Elsewhere this style has been termed the "physician as agent" style (Gattellari et al. 2001, Mooney and Ryan 1993)

At first, this model of variation looks very fruitful, but on closer inspection there is a conceptual problem. This spectrum referred to in the literature is a unidimensional one, possibly better described as a continuum or cline. If these three models lie on a continuum, what is it that increases or decreases as you move along it? What is it that shared decision-making is the mid-way point with respect to?

The continuum approach (based on Charles et al. 1997) appears to map the degree of patient participation, or agency in their own healthcare decisions. To the left, the patient has little participation or agency; to the right their participation is maximal. Corresponding to this, the doctor's agency in the patient's healthcare (or the doctor's role as the patient's agent in the economic sense) seems to be maximal at the left, and declines as we move to the right. Decision-making is then thought to be properly shared if the doctor and the patient "participate simultaneously at all stages of the process" (Robinson and Thomson 2001:i35). But "informed choice" is probably not the best description of what is at the right-hand end of such a cline. The legal discourse that underpins the doctrine of informed choice and informed consent tends to narrow the focus of concern to providing sufficient clear information. Such discourses tend not to emphasise interactive reasoning, and in practice this approach tends to discourage participative decision-making (Tomamichel et al. 1995). In practice, informed consent in clinical trials may be "little more than a ritual" for many doctors (Edwards et al. 1998: 1212), and other authors have felt that patients may not understand enough information to give truly informed consent (Montgomery et al. 1997). Where this is the case, the patient can hardly be construed as having maximal participation or maximal agency over their own healthcare. The continuum model of variation therefore seems to break down with respect to modelling agency.

Similar difficulties occur at the other end. Paternalism can be more or less 'enlightened', and the degree of fit between the paternal agent and the patient can vary, such that patients' and doctors' preferences may, sometimes, be well aligned even at the extreme left-hand side of the spectrum.

In the middle is shared decision-making. We are left with a relative definition, but nothing very clear to relate to, when what we need is a concept that carries a description in its own right.

To summarise, the continuum view suffers by not modelling doctor-patient alignment as a distinct dimension of decision-making style. In addition, this approach models agency as a zero-sum game (one in which one actor can only make a gain if the other actor makes a corresponding loss). Recent discourse-based studies of medical interaction provide evidence that in fact it is not a zero-sum game: that patients may assert their views more often, and more communicatively, when doctors expand on their own views (e.g., Peräkylä 2002). This of course means that those doctors are constructing a context for the patients to be assertive in, by modelling them as entitled to know their clinical reasoning. This has ramifications for our terminology. The implication that we are dealing with a zero-sum game is exacerbated if the term “shared decision-making” is used. “Sharing decision-making” carries the connotation of being more about sharing power than about achieving mutual engagement. Additionally, the term “Shared Decision Making, abbreviated as SDM, is beginning to be used in the literature to refer to a specific, fixed set of skills and competencies (Wensing et al. 2002). The term “joint decision-making” may be preferable, in which the notion of achieving alignment is built into the telos, as it is with terms “joint project”, even though it might not be possible in particular instances to achieve unison. Another advantage of “joint decision-making” is that it stresses temporo-spatial contiguity – we talk of shared experience that may only be similar experience, not experience together; likewise shared responsibility. This orientation is important for my emphasis on the knowledge-producing and preference-producing work of dialogue in medical consultations, but I will retain the terminology of shared decision-making in this thesis, for continuity with the literature.

A more promising analysis than the continuum is to first describe the features of the styles we find in doctor-patient talk, and then to build up an array of the features of those styles and a description of how the features combine, and under what conditions, in practice. Revisiting their model, Charles et al. (1999a) have taken a more descriptive and a more dynamic approach along these lines. The spectrum from Figure 2.1 is remodelled as Figure 2.2 below, with more description of the poles, broken down by what Charles et al.

call “analytic stage”. We can then see what effect this has on the overall understanding of how styles vary.

A *paternalistic* style defines the doctor’s role as providing information, deliberating, and making the final choice of treatment. An *informed* style defines the doctor’s role solely as the provider of information which patients use in selecting a treatment option. The *shared* style defines information flow as two way, deliberation as done by both parties, and the final choice as made by both parties. Charles et al.’s revision makes it clear that the shared style can only be considered to be in between the other two styles on *some* dimensions.

	Paternalistic	↔	Shared	↔	Informed
Information	doctor → patient medical legal minimum		2-way medical and personal all relevant info		doctor → patient medical all relevant info
Deliberation	doctor (+ other doctors)		doctor + patient (+ potential others)		patient (+ potential others)
Final choice	doctor		doctor + patient		patient

Figure 2.2 Revised decision-making styles as elaborated spectrum (after Charles et al. 1999a)

In terms of information flow, paternalistic decision-making is much more in common with informed decision-making than either of the extremes has with shared decision-making. So, in these terms, paternalistic and informed decision-making styles are not opposite ends of the spectrum at all, despite their different political motivations. It is partly for this reason that the informative style has been criticised for reducing the physician-patient relationship to educator and student (Emanuel and Emanuel 1992), which creates the potential for a

sense of abandonment in patients (Quill and Cassel 1995). It has also been identified as less beneficial to patients than other approaches (Gattellari et al. 2001).

Elaborating a little on the styles “in between” shared decision-making and the others, we can identify the interpretive style and the deliberative style (Brown et al. in press, cf. Emanuel and Emanuel 1992). In the *interpretive* style the doctor’s role is to elicit and help clarify the patient’s values about treatment, and to help the patient translate these into a particular treatment choice. In the *deliberative* style the doctor aims not only to elicit but also to influence the patient’s values and expresses his or her opinion about the most appropriate treatment choice.

Charles et al. (1997, 1999a) prefer the interpretive model, and caution against the doctor conveying his or her own values as this may influence the patient’s treatment choice. Others (e.g., Brown et al. in press) argue that doctors should make their recommendations explicit, since patients can often infer them through latent patterning in the description of choices, and may be less able to challenge such merely implicit influence. They may also interpret the doctor’s implicit recommendations wrongly if they are not spelt out. And they may feel abandoned even under an interpretive style, if one takes the view that the doctor has particular expertise that the patient values (Little 1995), or if one takes the related view that interdependence (Campbell 1994) might be better ethical starting points than autonomy.

In Charles et al.’s later view (1999a), the patient’s role in interpreting information has been upgraded: patients ‘filter’ information to make it personally meaningful, and it is acknowledged that a consultation or decision may evolve from one style to another as it unfolds (Charles et al. 1999a: 655). However, Charles et al.’s movement towards a discourse view only goes so far. They seem reluctant to acknowledge one of the central insights of ethnomethodology that underpins the findings they cite, namely that interaction styles – both symmetrical and asymmetrical styles – are *always* jointly achieved (Maynard 1991, Cicourel 1973). A corollary to this is that negotiation, in some form, always occurs, and is the means by which consensus can be displayed, rather than the opposite of consensus as they describe it. I will therefore argue throughout this thesis that the move to

see the different styles as varying across multiple dimensions needs to be extended further than Charles et al. have so far extended it.

As a body of literature, the research on doctor-patient decision-making also seems somewhat reluctant to draw explicitly on theories of social action or language (cf. Coupland et al. 2001). When theory is explicitly drawn on, writers tend to associate Parsons (1951) with the paternalistic model of decision-making, but generally tend not to identify any particular social theorists with recent developments (although there are of course exceptions). This may be because medical anthropology has lagged behind other fields of anthropology in synthesising theories of structure and agency (cf. Pappas 1990). It may also reflect the complex interdisciplinary, interdiscursive and intertextual relations between clinical practitioners, health care researchers, social scientists and social theorists of various persuasions (cf. Moatti and Souteyrand 2000). Pappas (1990) describes these issues, in particular the agency-structure dialectic, using the examples of two highly influential theorists, Howard Waitzkin and Arthur Kleinman. As Pappas points out, Kleinman (e.g., Kleinman 1980, Kleinman 1988) analyses individual action at the level of the dyad, largely in terms of language and problems of 'translation'; his theory allows for "good and bad individual doctors", but does not account for structural or social causality, and does not (for instance) bring structure and local action into an account of asymmetry. Waitzkin, on the other hand (Waitzkin and Waterman 1974, Waitzkin 1991), has an essentially structural account, but according to Pappas fails to incorporate an understanding of action; for example, he misses the negotiation that takes place between individual doctors and patients in consultations over time, space, resources, and control. Pappas concludes that these two productive traditions need to, and can be, be brought together.

In summary, there have been a number of recent positive developments in the models presented in the literature, but there is still much to be achieved. Decision-making still needs to be more explicitly modelled. Its dimensions need to be specified with more delicacy. Explanations in terms of agency and structure that are implied but not necessarily intended in the models need to be deconstructed. The role of interaction in expressing agency and structure needs to be elaborated. Gattellari and colleagues point to the need for such work when they identify as an under-researched area the question of "how patients



perceive their involvement and how they make judgements about the relative decisional authority of themselves or oncologists” (Gattellari et al. 2001: 1876).

### 2.4.2 Decision-making as phase or as analytic focus?

Elwyn, Edwards and Kinnersley (1999) have argued that it is too early to prescribe a model for increasing the practice of shared decision-making, because its use is not well enough understood. They argue that we still need to assess the effects of “well-defined and skilfully implemented shared decision-making processes in real clinical contexts” and suggest that we may need to go beyond the analysis techniques currently used to assess the physician-patient interaction.

One of the reasons for our lack of a clear model of shared decision-making is that researchers are not sure whether to conceive of the decision-making part of the consultation as a *temporally* delineated phase of the consultation or as a more dispersed analytic focus on the consultation. Elwyn and colleagues characterise decision-making as the “neglected second half of the consultation” suggesting that attention is focussed instead on developing skills in uncovering and matching agendas, which presumably takes place in the first half of the consultation, drawing on Byrne and Long’s (1976) description of consultation phases, as shown in figure 2.3.

- I. Doctor establishes relationship with patient.
  - II. Doctor either attempts to discover or actually discovers the patient’s reason for attendance.
  - III. Doctor conducts a verbal or physical examination or both.
  - IV. Doctor, or doctor and patient, or patient (in that order of probability) considers the condition.
  - V. Doctor, or occasionally patient, details further treatment or investigation.
  - VI. The consultation is terminated, usually by doctor.

Figure 2.3 Byrne and Long’s “ideal” phases of GP consultation

This is an important observation, and no doubt the majority of GP consultations have something like this first part, second part structure, but this is not always the way in which consultations are structured, and in any case the temporal metaphor can mask other ways of looking at the issues. For patients with chronic diseases such as HIV, who see their doctors regularly, each consultation is like a “second half”. There is no need for a distinct phase of establishing the relationship, nor for a phase of establishing the reason for attendance. The diagnosis of HIV infection is well-established, and although there may be other conditions which need diagnostic investigation there is often no need for an examination phase, nor for a phase of considering the condition.

Does this leave Byrne and Long’s item V “detail further management”, and item VI, “terminate consultation”, as the only remaining phases of the routine consultation in HIV? Yes and no. For a pre-diagnosed chronic disease, the structure of the consultation is changed so that detailing further management is at some level what the whole consultation is about. There are elements of problem-solving, of considering the condition, and of relationship-building, but they are embedded within the task of making decisions about treatment and other forms of management. I will argue in chapter 5 that we can tease these issues out by considering the structure of consultations in terms of sets of semantic elements which may be analysed as temporal phases like those outlined by Byrne and Long (1976) or may be analysed as ‘functions’ which do not necessarily imply sequence (Gask and Usherwood 2002) or in terms of ‘steps’ or ‘competencies’ (Towle and Godolphin 1999). It is important to balance the dynamic and schematic aspects which together imply that participants do not do one thing then move on to the next thing but rather that they finish a number of processes which culminate in the achievement of some larger process.

Another reason for problematising the treatment of decision-making as a temporal phase is that my empirical data do not always fit such a model. Interactants sometimes appear to be in the middle of making a decision about something but then trail off into non-decision. Talk that seems to be preliminary to a decision suddenly turns into an acknowledgement that a decision has been made. My empirical focus needs to cover both decisions as interactive achievements and the processes of interactive decision-making in

action, which amounts to examining the processes of doctor-patient interaction more generally. This issue is taken up in Chapter 5.

## 2.5 Researching language as behaviour

One of the central problems in progressing the research agenda on decision-making is that the most widely-used research paradigms do not examine the details of how decision-making is realised as language, but rather treat the language as a black box which is somehow, non-analytically, known to contain decision-making. This provides clinicians with policy and research literature that leaves them to work out the linguistic strategies for practising shared decision-making by themselves. Of course many are doing this successfully, but it is not ideal pedagogically, nor from the research point of view.

Ironically, this problem results from a tendency to treat language as a 'transparent' conduit for meaning. A useful illustration can be found in recent work evaluating the use of a decision aid in primary care settings by Murray et al. (2001a, b), along with related editorials. Murray et al. conducted a randomised controlled trial on the effects of using an expensive multi-media decision aid. Compared with normal practice, using the aid enhanced women's understanding of the effects of hormone replacement therapy (Murray et al. 2001a) and men's understanding of treatment for benign prostatic hypertrophy (Murray et al. 2001b). This work was followed by an editorial claiming that "the revolutionary contribution of these new aids lies simply in making it clear that there often is a choice" (Deyo 2001:467). The research is indeed an important contribution, but one which raises a question: why have we not been able to make it clear that there is a choice using the ordinary spoken interaction of the clinic? It is a shame that Murray et al.'s study design, despite its careful attention to many other details, treats the spoken interaction between patients, doctors and clinic staff as either a black box or a non-variable, by omitting any observation of the difference that the use of decision aids makes on how doctors and patients talk through decisions. It is likely that such multi-media decision aids extend the potential for patients to participate in decision-making in particular and important ways that cannot be done through the spoken mode alone, but if so we need to know how and why these additional symbolic modes change the meanings made through

spoken interaction (which, after all, will always be the primary mediating modality for decision-making – cf. Elwyn, Edwards and Kinnersley 1999). This implies the need for a close knowledge of the nature of language when using other modes.

By contrast, Hoffman et al. (2003) provides an interesting comparison of a study in which language strategies are explicitly explored. Hoffman et al. found a tendency for doctors to downplay the risks of taking hormone replacement therapy (also studied by Murray and colleagues). For example, doctors recontextualised the risks of taking treatment as “drawbacks”, while reserving the term “risks” for the risks associated with not taking treatment. When women spoke about their concerns, doctors’ responses were generally to emphasise the benefits. Several other patterns were found which together produced a consistent but covert semantic effect of recommendation for treatment, despite the declared purpose being “information only”. It is possible that the “the same information”, when presented in the form of a decision aid, is presented in a more equitable way. It is also possible that, having viewed the decision aid, women were able to present their concerns and follow them through with their doctors to a more satisfactory conclusion. Many other reasons for the success of the aid are possible, but we cannot explain it or generalise from it without more information about the language involved in the aid and in the interactions in which it was used.

Among the directions proposed in the literature about shared decision-making which do focus on linguistic and interactive strategies, one recurring recommendation is that doctors should encourage patients to ask more questions (e.g., Stewart 1995). Strategies for how to do this often take the form of suggesting that doctors say at the outset of a consultation that the patient should “feel free to stop them if they have a question”, or words to that effect (Brown et al. in press). Other authors emphasise the role of doctors asking open-ended questions, which are not limited to the aim of getting patients to ask questions back. For example, Mishler (1984) stresses the role of various types of questions from the doctor, arguing that sequences of closed questions from the doctor create a cohesive structure based on the voice of medicine, whereas open-ended questions can create a different cohesive structure oriented to the voice of the lifeworld: open-ended questions facilitate patient elaboration and the joint building-up of an account in the patient’s terms (cf. McInnes et al. 2001). Both using open-ended questioning and

encouraging question-asking from the patient are useful as strategies for enhancing patient participation. However, for progress to occur in research and practice it is important to consider how we theorise the relationship between question-asking and participation. From a discourse point of view, question-asking is language behaviour at the clause or message level, whereas participation in decision-making is something located on a different temporal and explanatory scale (cf. Lemke 2000b). Moreover, whether a message is an open-ended question is clearly only one dimension of its nature. Each message, whether it is a question, statement, offer or command, has many simultaneous features which might help it enhance participation or might close participation down, and both effects can be produced by the same message (cf. Halliday 1973). For instance, a speaker may articulate a question him or herself but represent the information-seeker as someone else, and this can be done for other speech functions as well (Goffman 1981, Levinson 1988). Beyond that, a box of messages does not constitute a text or an interaction: the messages have to be organised and related to each other and to their context in various ways – sequentially, compositionally, logically, instantially and so on. These factors will have a bearing on the contribution that any utterance, or type of utterance, such as the question, has on the level and type of participation achieved in any interaction.

Thompson (1999) examined all the questions made by both patients and doctors in four consultations, and found that doctors and patients used different types of questions. For instance, doctors used a high proportion of “declaratives” such as “So it gets worse overnight.” while patients did not use this form at all. Here the doctor is both giving information, a speech role associated with knowledgeable status, and seeking confirmation. This type of question has a complex effect on patient participation, and carries the potential to either amplify the patient’s voice or diminish it. Research on shared decision-making therefore needs to be able to examine in some detail a broad range of dimensions of language behaviour, and to show how that micro-level behaviour is related to categories of social practice. While it may not be possible or appropriate for every study to examine all these factors in detail, it is important to be able to locate the phenomena being studied within a framework that can specify the relevant dimensions when necessary.

This paradox of the opacity of language is not limited to holding back research; it is a pervasive attitude to language and interaction that is reinforced by the research-teaching-

practice cycle. Linguistic and interactive strategies – which are really the stuff of negotiating decisions and styles of deciding – are not seen to require a theoretical account, and often do not receive an empirical account either. A recent influential manual for evidence-based clinical practice is a case in point (Guyatt and Rennie 2002). It provides a pithy ten-page review of the literature on incorporating patient values into decision-making, citing 31 strategic references to support claims about issues such as whether decision aids influence patient satisfaction and decision outcome. At the same time they feel able make an unsupported assertion – a major unsupported assertion in a book about using evidence – that “patients who prefer a parental approach tend to quickly chasten clinicians who try to communicate the benefits and risks with admonitions such as, ‘You’re the doctor’” (Guyatt et al. 2002: 572). On what basis can particular wordings such as “You’re the doctor” be understood as a particular kind of interactive behaviour, such as admonishing, and in what kind of context? Here is a missed opportunity to suggest that clinicians might benefit from a critical approach to models of meaning-making, and that such models need to be theorised, generalisable and supported by evidence.

It is helpful to also consider limitations imposed on the research agenda by focusing only the spoken mode of language. Hak (1999) has argued that the focus on close analysis of verbal interaction between doctors and patients, which he refers to as the “discursive gaze”, is responsible for a kind of decontextualisation of problems in health and health care in rather the same way that the “clinical gaze” decontextualised the patient’s experience of ill health. As Hak (1999: 442) puts it “the problem of biomedicine and the ‘clinical gaze’ is not ... that biomedical scientists and clinicians make claims about what is beyond their data but rather that their claims (and successes) are restricted to data that often have only a spurious relation to patients’ illness experience. The result is that research problems of health and illness are formulated in biomedical terms by default.” Hak quite rightly argues that as a body of work, social research on medical practice now over-represents powerful players whose verbal interactions are amenable to observation and objectification in the form of audio recordings and their transcripts (doctors rather than dietitians, physicians rather than surgeons). He calls for the ‘embedding’ of conversation analysis and discourse analysis approaches within a broader ethnographic endeavour.

But Hak's metaphor of 'embedding' may not be the best way of characterising the relationship between language and context. If discourse and context are thought of as mutually constituting each other (Malinowski 1923, Cicourel 1973, Goodwin and Duranti 1992 *inter alia*), then a more useful metaphor might be realization or instantiation (Halliday 1973). The increased understanding of adherence is a case in point. As Hak points out (1999: 443), although non-adherence has presumably been pervasive for ever, it was not known to researchers for a long time, and failure of a drug treatment was attributed by default to features of the drug. Increased appreciation of "the compliance problem" has drawn on a wide range of methodological approaches, from history (e.g., Lerner 1997), in-depth interviews (e.g., Donovan and Blake 1992, Race et al. 1997), and biostatistical and epidemiological techniques such "intention to treat" (e.g., Urquhart 1991, cf. Guyatt and Rennie 2002), to approaches which might be described as action research or community media campaigns (Batrouney 1997a, b). Discourse analysis of various kinds has a role to play in the former, and in more text-analytic approaches (McInnes et al. 2001, Candlin et al. 1998). However, as the corpus analysed in this thesis shows, adherence-aware doctors still engage in the kind of reasoning that Hak describes, in which drug action is the default explanation for "results" observed, and this has the potential to frustrate shared decision-making. It is doubtful whether this would be shown up by ethnographic studies that did not focus closely on the verbal contributions doctors make in consultations, since the doctors recognise adherence/ compliance as a ubiquitous issue (cf. Jones et al. 2000). The point here is both a practical and a theoretical one. From the point of view of this study, explanations of treatment effectiveness are realised – at least primarily – through language. This is the case whether or not they are explicitly given as explanations and whether or not they are multi-modally realised (e.g., through tables or graphs on paper or screen). Of course in "default explanations" the "defaultness" typically cannot be explicit but must be inferred from some aspects of the latent patterning of the talk, or from considering what was said in relation to aspects of context not made manifest in that particular interaction, but which can be brought into the same analytic frame as the talk, that is, the frame of meaning potential. So, whether discourse analysis is foregrounded or ethnographic analysis is foregrounded must depend on particular research perspectives; and the relation between discourse and context is not just a matter of the balance achieved in any one study,

but also across research programs and fields. In this thesis, rather than seeing language in terms of events embedded in pre-formed contexts and practices, contexts and practices are seen as perspectives on meaning. Most importantly, the language through which doctors and patients discuss compliance/ adherence/ concordance is crucial to the way it is constructed as an institutional practice (RPSGB 1997, Mullen 1997, Candlin et al. 1998, Moore et al. 2001).

## 2.6 Summary of this chapter

As I hope is clear by now, the literature on shared decision-making in health care is largely concerned with the agency and autonomy of the patient. Another dominant theme of this literature that I have tried to draw out is a concern for the degree to which patient and doctor are aligned in their understanding and views. Running between these is the doctor's expertise – expertise in enhancing the patient's sense of agency and in maximising doctor-patient alignment, as well as in negotiating technicality (more often conceived of as translating technical information into lay terms).

In her review of decision-making styles in medicine, Stewart (1995) discerned four key elements:

1. the provision of clear information
2. questions from the patient
3. willingness to share (discuss decisions)
4. agreement between the patient and doctor about the problem and the plan

When viewed through the perspective of the more discursive approach argued for here, with its emphasis on the interactional negotiation of meaning, we can reconstrue these elements as three dimensions:

1. doctor and patient jointly *negotiate* relevant *technical* and *non-technical* discourses
2. doctor and patient construe the patient as an active *agent* of their health, and of decisions about their health
3. doctor and patient achieve *alignment* about the terms in which the problem and plan are to be viewed, and seek agreement but may agree to differ.



In the above discussion I have indicated that there are fairly certain to be benefits from doctors and patients making treatment decisions together. But, despite a growing literature, we still lack a clear model of shared decision-making that shows how it is realised in practice and how it can be distinguished from other styles of decision-making. Researchers are calling for ways of characterising decision-making which are more comprehensive and which can account for the different types of decisions that are made (Gattellari et al. 2001, Ford et al. 2000). In order to meet this challenge, we need to put the flesh of detailed discourse description on the bones that comprise the considerable research effort of recent years. As Elwyn, Edwards and Kinnersley (1999) suggest, this will require new techniques, or perhaps new combinations of existing techniques from neighbouring fields that are well suited to answering the pressing question of how decision-making is realised in practice.

Alongside “design, implement, then test” studies on specific decision aids and doctor training, we need descriptive studies based on close analysis of routine consultations which can identify crucial discursive strategies that doctors and patients have developed and are using to achieve shared decision-making. As I have suggested above, shared decision-making appears to be more prevalent in HIV medicine (Prestage et al. 2001, Race et al. 2001, Moatti and Souteyrand 2000) than in other fields of medicine. Studying HIV treatment consultations therefore gives an excellent opportunity for examining shared decision-making as a style, as well as being part of a broad research strategy aimed at supporting people with HIV and their doctors.

In the next chapter I describe the data on which my study is empirically based, present some general findings, and outline some principles and techniques for additional analysis.



# 3

## Framing the study: data and methods

No language has the “last word” on the terms of metalinguistic description, whether they be terms like tense, aspect, mood, accusative etc. or greeting, excursus, parable, analogy, syllogism and so on. The crucial issue is to bring a motivated order to the plethora of potential discriminations/ terms.

Butt (2000a: 8)

In chapter 1, I outlined why a descriptive study of shared decision-making in HIV medicine is needed, and why a discursive approach would be the best way of answering many of the questions that need addressing. Relevant literature addressing these and other questions was reviewed in chapter 2, and both chapters raised a number of methodological issues. This chapter sets out some additional details about the design of my empirical, descriptive study of shared decision-making in HIV medicine, the data my study produced. The chapter also presents an overview of what might in some paradigms be considered “results”; but in discourse research the line between data and results is particularly problematic, and it is useful to combine some aspects of both methods and results in this chapter, as background for what follows.

### 3.1 About the study

This study is essentially a qualitative observational study of doctor-patient consultations in the field of HIV as institutional practice and, more broadly, social practice. Audio-recordings of the spoken interaction taking place in routine consultations comprise the primary data<sup>1</sup> in this study<sup>2</sup>. As discussed in chapter 2, this “speech stream” is only one component of the multiple streams of symbolic and material action that make up each interactive event; however, the empirical component of the study is limited to this modality, largely for reasons of research ethics (research observation and video recording were considered too intrusive and too threatening to anonymity). The consultations were audio recorded by the doctors in their offices in the greater Sydney area between 1995 and 1997.

Study participants were recruited via a compromise between purposive sampling and the snowballing technique. Doctors who were members of the Australasian Society for HIV Medicine (a purposive sample) were contacted via a letter from one or more of the research team, which was followed up with a phone call and often a visit to discuss participation. If doctors agreed to participate they would then approach suitable patients. It was left for the doctors to decide which of their patients to approach, but the doctors were told that the researchers were interested in cases in which the patient and doctor already had an established clinical relationship, and in which the diagnosis of HIV was not recent news (it was left to the doctors to decide interpret this criterion). Doctors were asked to tape a series of five consecutive consultations with up to five patients. In the event, some produced longer series than this and most produced shorter series.

The study did not attempt to achieve a representative sample, largely because the sensitive nature of the research ruled out the complete enrolment of a random sample. There was an attempt, however, to include both inner city (gay Sydney) practices and suburban practices, and both private and public services, and this was

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<sup>1</sup> The term “data” will be treated as a mass noun and therefore as singular throughout.

<sup>2</sup> The study reported in this thesis draws on a broader study of Effective HIV Healthcare Management in HIV/AIDS. CN Candlin, GA Plum and S Kippax, Investigators. Funding was received from the National Health & Medical Research Council, Australia, and the Macquarie University Research Grants Scheme.

achieved. The sample is skewed towards city practices, gay male doctors, and gay male patients. It is probably also skewed towards reasonably assertive, socially skilled patients, since doctors will have selected others out; and towards doctors interested in communication and research, or who did not feel too threatened about having their communicative expertise scrutinised. Many of the doctors who were approached but did not want to participate in the study used the argument that good clinical communication could not be captured and analysed, or taught explicitly.

It was originally planned to collect interview data with patients and doctors about their views on the interactions recorded, but this proved not to be possible<sup>1</sup>. The study draws on other data as secondary data, including treatment guidelines for practitioners and support material for patients, obtained from community newspapers, journals and websites, as well as data from in-depth interviews with people living with HIV published by the National Centre for Social Research in HIV (e.g., Race et al. 1997). Most of these external sources of data have not been subjected to any systematic analysis, but rather have been drawn on when necessary to exemplify important aspects of the context of considering and reviewing HIV combination therapy in Sydney in the late 1990s. An exception is that a small segment of Race et al's interview data in which a patient reflects on treatment is explored in some detail.

### 3.2 A corpus of interactions and decisions

The transcribed speech data can be seen from one perspective as forming a corpus of decision-making interactions in HIV medicine, and from another perspective as forming a small corpus of register-specific spoken interaction. In this thesis the former perspective will be the dominant one.

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<sup>1</sup> Lack of time beyond commitments for taping and recruiting were the main barriers for doctors and anonymity and time commitments were the main barrier for patients. Many of the doctors and patients were involved in other studies including clinical trials.

### **3.2.1 The interactants and their interactions**

The corpus comprises 74 consultations across 22 different doctor-patient dyads, comprising 22 patients and 7 doctors. Most of the consultations were two-party interactions between an HIV+ man and his male GP, in a private practice with high HIV caseload. In addition there was one GP with a low HIV caseload, and there were also two specialists working in a clinical/academic department or a clinic attached to a teaching hospital (i.e., in the public sector). One of the GPs was female. Most of the patients were gay or homosexually active men who attributed their infection with HIV to having gay/homosexual sex. Four of the patients were women, some of whom had contracted HIV through donated blood before blood screening began. At least three of the patients had been injecting drug users, and two had Hepatitis C diagnoses in addition to HIV.

All of the patient/doctor dyads were established clinical relationships and had known the patient's HIV status for some time. All of the patients were reasonably well at the time of the study in terms of the manifestations of HIV disease, although some had had periods of HIV-related illness in the past.

Additional participants involved in the interactions included: in one consultation, the patient's partner; and in 8 consultations, a practice nurse, trial nurse, or advanced trainee doctor or nurse. Researchers were not present in any of the consultations.

### **3.2.2 The treatments in use**

Between the pilot study (1995) and the main period of recruitment and recording for the study (late 1996–1997), new treatments for HIV were developed which were much more effective, much more accessible and much more consensually advocated by leading researchers, practitioners, lobby groups and patient support groups. There was not yet a complete consensus or any well-established model of prescribing practice telling doctors when to begin treatment, how to choose from available options, which options would together achieve which effects, what would be the results of interrupting treatment, or of serial changes to treatment. The timing of the study made it possible to observe some doctors and patients negotiating their way through genuinely new information, and through competing potential strategies such

as whether to ‘hit early and hit hard’ or to ‘keep some options up one’s sleeve’ for later.

Among the 22 patients in the study, 14 were using combination anti-retroviral therapy, also known as highly active anti-retroviral therapy (HAART), and most of these were on a combination of three specific anti-retroviral drugs. During the course of the study, as far as the recordings show, 2 additional patients decided to initiate combination therapy. Six patients were not on any anti-retroviral therapy during the period in which they were recorded, although some of these had been on an earlier form of treatment, such as AZT given alone (monotherapy). These 6 patients were recorded before combination therapies were accessible and promoted, or during the early transition period. During this period some of our respondents were on early combinations (dual therapy).

Table 3.1 Patients on antiviral drugs in this corpus

Patients on HAART	Patients about to initiate HAART	Patients not on HAART
Stephen	Jeremy	Carl
Philip	Joan	Jonathan
Todd		Brian
Bruce		Max
Darren		Dorothy
Neil		Melissa
Peter		
Oscar		
Michael		
Murray		
Kate		
Victor		
Jamie		
Boris		

In addition, most patients were either using other medicines on a long-term basis or sought and/or received treatments for incidental problems during the course of the recording. Common treatments which related to HIV infection or treatment included:

- routine use of Bactrim tablets or other antibiotic prophylaxis against serious chest infections
- routine use of fluconazole for various fungal skin infections

- the freezing and manual removal of anal warts
- use of grapefruit juice or Zantac as way of enhancing the absorption of HAART drugs.

### **3.2.3 The elusive decision and the question of what to study**

If most of the participants in the study are already using combination therapy, it might be expected that there is little for this data to show us about the character of decision-making, since the 'main event' of deciding whether to start treatment, which combinations to use and why, are obscured from view. The counter-argument made in this thesis is that decision-making – especially in professional practice – is not a bounded event, but an incremental, recursive and elusive process (cf. Boden 1994, Atkinson 1995). Sarangi and Roberts (1999) speak of ways in which decision-making in social life 'escapes' from view. It is also important to keep the macro perspective in view when one is focussing on the micro (Cicourel 1992). A number of implications flow from taking this perspective.

1. Treatment decision-making should not be seen as occurring only at those points in a consultation between a doctor and a patient where it is explicitly topicalised or foregrounded.
2. In the context of ongoing treatment for chronic conditions such as HIV, it may be important to think of decision-making both as a process and as a cycle of decision and review. Such cycles must be considered to be motivating clinical interactions in ways over and above those which can be isolated as local activities (such as 'reviewing side effects').
3. From the professional and institutional perspectives, beyond this cycle of decision and review for each patient as an individual is the cycle of decision and review about treatments for the 'population': which treatments are considered clinically and economically appropriate for which conditions and which patients, as reflected in (for example) changing treatment accessibility, pricing, and promotion.



4. There are similar 'behind the scenes' cycles for patients as well, based especially on information in the gay community press, on the internet and in HIV support groups (cf. Jones et al. 2000).

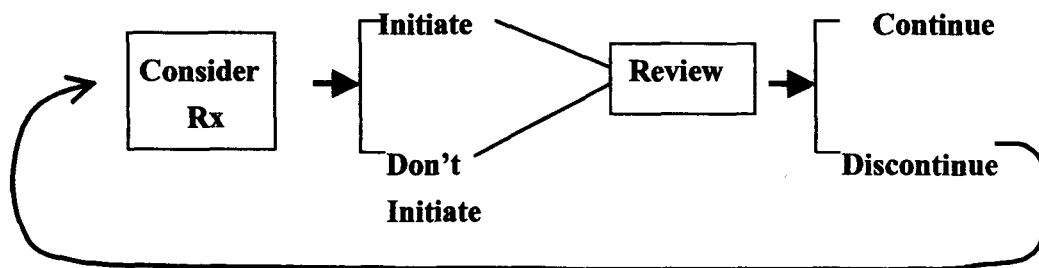


Figure 3.1 Decision-making represented as a cycle over repeated consultations

As a result of these considerations, it is not enough for research on shared decision-making to focus on only those consultations in which initiating, stopping or changing therapy is explicitly discussed, or on those passages of interaction where decision-making is foregrounded. In order to achieve a comprehensive model, the analytical object of scrutiny must encompass the character of doctor-patient interaction more generally, in the environment of ongoing clinical relationships, and in the context of ongoing professional, institutional and social considerations (Cicourel 1992). This contrasts with the direction taken by some of the most influential research on shared decision-making, in which decisions tend to be treated as bound events which start with the doctor or patient foregrounding decision-making in an explicit way (e.g., providing information to the patient about options), and which finish when the chosen treatment is announced in the 'actual decision making' (Strull et al. 1984) or the 'final choice' (Charles et al. 1999a). We could call this the particulate view – decision-making as a constituent element of some larger activity.

While attending only to the particulate structure of decisions may work well enough in studying unilateral decision-making, it is likely that as decision-making

becomes more shared it also becomes more dispersed throughout the interaction.<sup>1</sup> As the temporal horizon framing the object of scrutiny expands, a shift in focus is also required – from those discourse practices which constitute the ‘main event’ of decisions (i.e., places where deliberation is put on record) to the *discourse environment* more generally. The idea of discourse environment refers to the habitual ways in which a doctor and patient relate to each other, and their meaning-making history, and includes the momentary ebb and flow of opportunities to make or review decisions, which may get taken up or not. Given all of the above, this study takes into account:

- i) those places in the texts of the taped consultations where deliberation is put on record;
- ii) the interactional habitus of the doctor and patient, insofar as the taped consultations provide insight into that; and
- iii) the temporal plasticity of decision-making as a strand of interaction.

### 3.2.4 A corpus of consultations as spoken interaction (texts)

The close analysis of ‘critical moments’ (Candlin 1997) such as the discussion of viral load results, or the enunciation of a particular treatment decision, can be complemented with an analysis of relevant patterns across the corpus. This allows me to consider to what extent the interactive patterns which constitute such ‘critical moments’ are typical or atypical of the discourse between doctors and patients more generally, although the limits of generalisability in and beyond the study are kept in mind.

Owing to the complexity of the phenomena under scrutiny, sampling issues, and the amount of analysis required, it was not possible take a comprehensive corpus-analytic approach as well as a close interpretive approach to the data. Using text analysis to illuminate discursive strategy calls for a contextually sensitive, semantically oriented grammatical analysis drawn up on functional grounds, and

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<sup>1</sup> It is beyond the scope of this study to test this hypothesis in a rigorous way since a different study design would be required, but it appears from the present data to be likely. It would still be important to study the discourse environment of unilateral decisions.

techniques have not yet been developed to do this other than manually (Matthiessen et al. 1991) despite useful recent developments which attempt to mechanise some of the second-stage processing (Wu 2000, O'Halloran 2000). One instance of computational analysis of medical consultations was found in the literature which supports this view. Thomas and Wilson (Thomas and Wilson 1996) reported that their computational analysis of medical consultation data, based on what they called automatic semantic tagging (tagging for lexical word and word class), did not perform well in identifying what they called pragmatic strategies. Automatic semantic tagging such as that used by Thomas and Wilson would be unlikely to help identify the more latent semantic patterns and the interaction effects of grammatical choices discussed in this thesis, although such approaches may be useful for testing their generalisability across different corpora and different contexts.

The 74 transcribed consultations were exported into a set of relational database files<sup>1</sup> and stored at various levels of analysis. The consultation texts had already been marked according to turns during transcription, using a definition of turns that allowed minimal verbalisations to appear as a turn. Selected texts were then manually divided into clause complexes and clauses. Although no attempt was made to be statistically “representative” of any particular linguistic or contextual features, such selections were made from transcripts which

- i) contained explicit, on-record deliberation;
- ii) appeared to be important instances of performing/reflecting particular agentive roles, whether engaged in deliberation or not;
- iii) appeared to demonstrate the more elusive presence of decision-making.

Consideration was also given to dividing analytic attention between texts and passages of texts to cover decision-making

- i) about initiating treatment and reviewing treatment;
- ii) regarding different types of treatment;
- iii) appearing to be unilateral and appearing to be collaborative.

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<sup>1</sup> The databases were based on Filemaker Pro software, customised by Christian Matthiessen and Wu Canzhong. Additional customizing was done by Jason Grossman, Annabelle Lukin and myself.

Table 3.2 Summary of spoken corpus – size of corpus

Unit	Total	Analysed for grammatical features
Transcripts	74	71 <sup>1</sup>
Turns	18872	
Clause complexes	5658 <sup>2</sup>	
Clauses	6462	2616 <sup>3</sup>

### 3.2.5 A corpus of decisions about combination therapy and other treatments

From the first point of view described above, approximately two-thirds of the consultations involve decision-making about combination therapy (HAART) in some respect – from whether to start treatment at all, to whether the treatment is working, whether new complaints may be attributable to the medicine, and so on. Whether they involve extended discussions or brief visits to the issue of combination therapy, these interactions provide useful insights into the character of decision-making about HIV treatments in day-to-day practice, and of decision-making more generally.

Table 3.3 Decisions about antiretroviral combination therapy in this corpus

<i>Con- sult ID</i>	<i>Dr</i>	<i>Patient</i>	<i>HAART decision outcome</i>	<i>SDM-HAART?</i>	<i>P on Rx?</i>
1	Martin	Philip 1	change combo	3rd party, reported	Y
2	Martin	Philip 4	monitor combo but anticipate change	unilateral -D; SE & response queried by P	Y
3	Martin	Philip 5	keep combo, anticipate move to trial	unilateral -D deferred, P queries trial	Y
4	Martin	Philip 6	monitor combo - results not back	-	Y

<sup>1</sup> At least an overview of GSP/phase.

<sup>2</sup> Manually parsed subset

<sup>3</sup> Manually parsed subset. Includes at least transitivity/ergativity analysis; additional analyses given where of interest. Interpersonal analysis of selected passages.

Con- sult ID	Dr	Patient	HAART decision outcome	SDM-HAART?	P on Rx?
5	Martin	Philip 7	enact nelfinavir	SDM P-scaffold	Y
6	Martin	Jeremy 1	-	-	N
7	Martin	Jeremy 2	Refuse AZT, entertain other antivirals	SDM D-scaffold	?
8	Martin	Stephen 1	changing combo - P has just started	unilateral -D but ? last consult	Y
10	Martin	Stephen 2	take zantac not grapefruit; monitor SE	SDM P-scaffold	Y
11	Martin	Stephen 3	change anticipated blood taken	unilateral -D	Y
12	Martin	Stephen 4	keep combo (results unequivocally good)	unilateral -D but minimal enunciation	Y
13	Martin	Stephen 5	monitor combo blood taken	-	Y
14	Martin	Stephen 6	keep combo	unilateral -D P attempts coda ?	Y
15	Martin	Stephen 7	interrupt d4T (to fix peripheral neuropathy)	unilateral -D, P wants to change saquinavir?	Y
16	Martin	Stephen 8	-	P initiates repeat for saquinavir	Y
17	Martin	Stephen 9	get combo repeats	-	Y
9	Martin	Stephen 10	get combo repeats	-	Y
18	Martin	Carl 1	-	-	N
19	Martin	Carl 2	-	-	N
20	Trevor	Todd 1	project change combo P refuses nurse mtg	unilateral -D but ? earlier consult	Y
21	Trevor	Todd 2	change combo	unilateral -D	Y
22	Trevor	Bruce 1	anticipate change compliance explored	-	Y
23	Trevor	Bruce 2	take bloods	-	Y
24	Trevor	Bruce 3	keep combo, VL = 0	SDM obvious choice	Y
25	Trevor	Bruce 4	-	-	Y
26	Trevor	Bruce 5	-	-	Y
27	Trevor	Bruce 6	-	-	Y
28	Trevor	Darren 1	-	-	Y
29	Trevor	Neil1	change combo indinavir -> saquinavir	SDM D-scaffold	Y
30	Trevor	Neil2	blood taken	-	Y
31	Trevor	Neil3	change combo again, from AZT -> d4t +	SDM D-scaffold	Y
32	Trevor	Peter1	keep combo - dual (AZT, ddI)	SDM D-scaffold	Y
33	Trevor	Peter2	keep combo despite query VL = about 1000	SDM, D/P	Y
34	Trevor	Peter3	-	-	Y
35	Trevor	Oscar1	anticipate change combo	SDM D-scaffold	Y
36	Trevor	Oscar 2	-	-	
37	Trevor	Michael 1	keep combo (d4T ddI and nevirapine?) but anticipate	SDM P-coda	Y

Con- sult ID	Dr	Patient	HAART decision outcome	SDM-HAART?	P on Rx?
			change and monitor		
38	Trevor	Michael 2	bloods but no vl	unilateral -D not to test	Y
39	Trevor	Michael 3	anticipate change (blood taken for "cruncher" test	SDM D-scaffold	Y
40	Tony	Jonathan 1	-	-	N
41	Tony	Jonathan 2	-	-	
42	Tony	Jonathan 3	-	-	
43	Tony	Jonathan 4	-	-	
44	Tony	Jonathan 5	-	-	
45	Tony	Jonathan 6	stay off Rx	unilateral -P	
46	Tony	Jonathan 7	-	-	
47	Tony	Jonathan 8	-	-	
48	Tony	Brian 1	stay off Rx	unilateral -P	N
49	Tony	Brian 2	-	-	N
50	Tony	Brian 3	stay off Rx	unilateral -P	N
51	Tony	Brian 4	-	-	N
52	Roland	Dorothy 1	-	-	N
53	Roland	Murray 1	keep combo, early dual of AZT + 3TC	-	Y
54	Roland	Murray 2	-	-	Y
55	Roland	Kate 1	monitor combo Tcells test but no VL	-	Y
56	Roland	Kate 2	-	-	Y
57	Roland	Melissa 1	stay off Rx, as Tcells high	unilateral -D	N
58	Karen	Joan 1	initiate Rx	SDM D-scaffold	N
59	Karen	Joan 2	initiate dual therapy	SDM P-scaffold	N
60	Sam	Victor 1	monitor combo	SDM	Y
61	Sam	Victor 2	blood taken, monitor adherence	-	Y
62	Sam	Victor 3	keep combo, vl=0	SDM	Y
63	Sam	Victor 4	blood taken	-	Y
64	Sam	Jamie 1	project change re SE already changed once	SDM P-scaffold	Y
65	Sam	Jamie 2	stay off -ritonavir	SDM P-scaffold	Y
66	Sam	Jamie 3	stay off -ritonavir	unilateral -P tho projected only	Y
67	Sam	Jamie 4	keep combo (good results + feel well)	SDM P-scaffold (more agreed)	Y
74	Sam	Jamie 5	keep combo as VL =0 (not try nelfinavir)	SDM P-scaffold (very joint, from results)	Y
68	Sam	Boris 1	monitor combo waiting for VL	-	Y
69	Sam	Boris 2	-	-	Y
70	Sam	Boris 3	put off bloods	SDM P-scaffold	Y
71	Sam	Boris 4	agree to do bloods (next week)	unilateral -D, moving towards SDM	Y
72	Sam	Boris 5	change combo, but defer which combo	SDM P-coda	Y
73	Dennis	Max 1	-	-	N

An interpretive assessment of the style of each decision was made, based largely on the realization and sequence of generic phases, but also drawing on substantive information in the consultation. A decision was classified as unilateral if any of the following conditions were met:

- One party had already initiated or stopped treatment without discussing it with the other.
- One party presented the treatment decision discursively as having been made, or made an enunciation without any deliberation.
- There was evidence that the interactants disagreed but one party's view prevailed and a plan was set.

While all of these criteria are themselves interpretative, the aim here was to guide and frame a more detailed examination of particular decision-making episodes, in order to examine how and why the participants used shared and unilateral styles (Peräkylä 1998, 2002).

Table 3.4 HAART decision outcomes and decision-making style in this corpus

Decision-making style	Shared	Unilateral-P	Unilateral-D	TOTALS
<b>Decision outcome (antivirals)</b>				
initiate Rx	2	0	0	2
don't initiate Rx	1	3	1	5
keep Rx	8	1	3	12
change Rx	5	0	3	8
project change	4	0	5	9
routine monitor	10	0	1	11
<b>TOTALS</b>	<b>30</b>	<b>4</b>	<b>13</b>	<b>47</b>

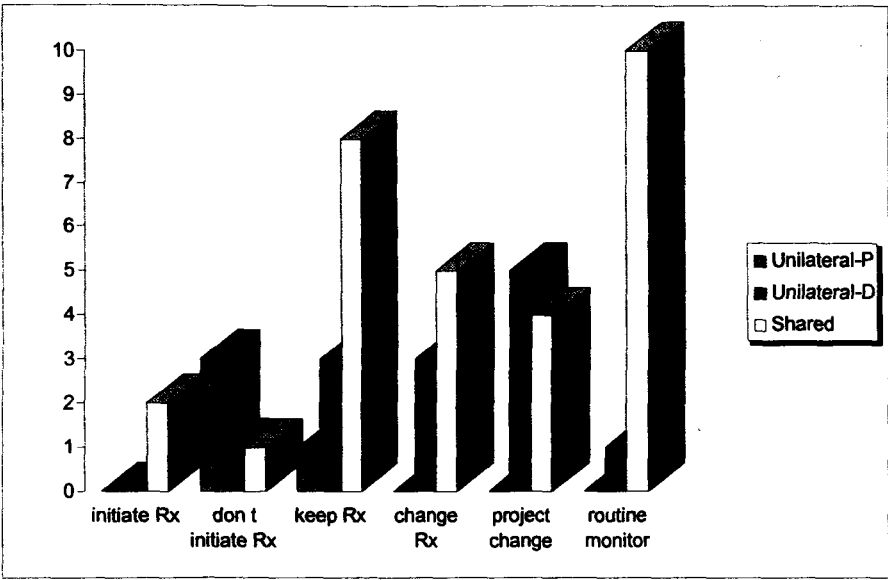


Figure 3.2 Decision outcomes re HAART and decision-making styles in this corpus

Figure 3.2 and Table 3.4 show the number of decision-making episodes about HAART in the corpus, defined broadly as any discussion of antiretroviral treatments that the patient is using, or any evaluation or preparation for evaluation of viral load results and other markers while the patient is taking combination therapy, or any discussion of the possibility of initiating or changing combination therapy.

As Table 3.4 shows, among all episodes of decision-making or decision preparation about HAART, a shared decision-making style is the most common style (30 out of 47 episodes). Where there was a projected decision that a change of antiviral drugs would probably be needed, which may or may not have ended up being implemented, unilateral decision-making by the doctor was more common, as shown in Table 3.4 and Figure 3.2. Where there was a decision not to initiate antiviral therapy, this was likely to have been made by the patient unilaterally. In four instances a patient refused to consider any antiviral drugs because of having had bad experience with AZT during the “pre-combination therapy era” of HIV healthcare.



3.2.6 Other decision-making

In addition to talking about HAART, the doctors and patients in this study deliberated and decided about a range of other types of treatment, and about logistic issues and personal issues like going to counselling, changing jobs and ‘marital issues’, all of which are related to health management and patient care but are for the most part not considered here to be treatment decisions.

As Table 3.5 (below) shows, a shared decision-making style was the most frequently observed style for non-HAART decision-making episodes, as well as for decisions about HAART. In this dataset, decisions about other matters were more likely to be undertaken as shared decision-making than were decisions about HAART, as indicated in Figure 3.3. Since HAART was by no means a treatment with clear best practice recommendations at the time of the study, the finding that patients and doctors are somewhat *less* likely to share decisions about HAART than about other matters (which may involve less clinical uncertainty), suggests that it is important to study further the reported link (e.g., Elwyn, Edwards, Gwyn and Grol 1999) between a high level of uncertainty about best treatment and a high level of patient participation in decision making.

Table 3.5 HAART and non-HAART decision outcomes and decision-making style in this corpus

Decision making style	Shared	Unilateral P	Unilateral D	Other (eg 3rd party)	TOTALS
Decision Outcome					
HAART	30	4	13	2	47
Other	39	3	8	6	56
TOTALS	69	7	21	8	103

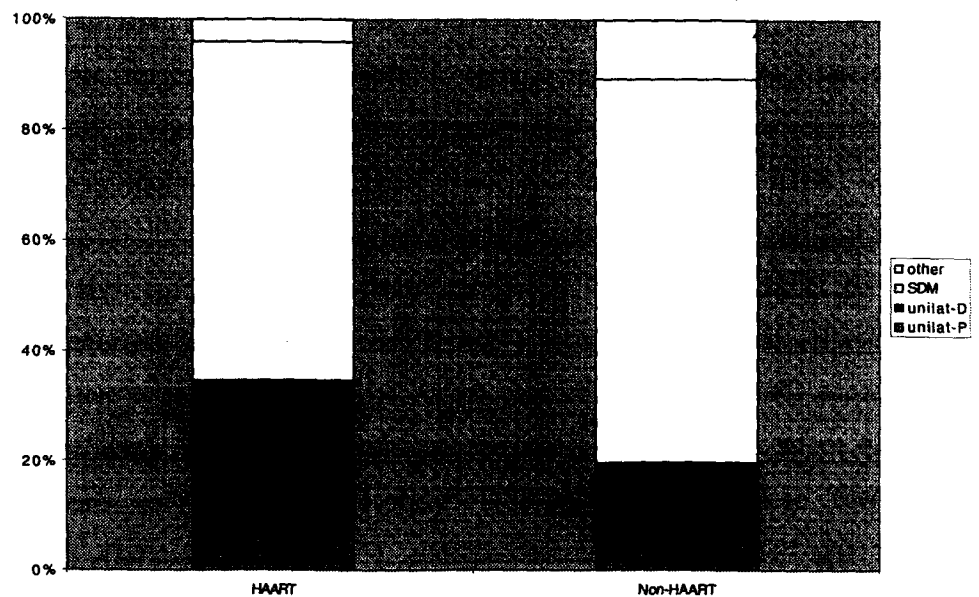


Figure 3.3 Proportion of decisions shared: HAART cf. non-HAART decisions

As the numbers in this study, and particularly in each cell, are small, these descriptions of the distribution of shared decision-making should be treated as suggestive only. Additionally, the classifications are by no means based on robust criteria, and this is partly because these phenomena are analysed interpretively, and partly because the literature on shared decision-making has not tended to provide data of the actual interactive practices that are taken to realize it (e.g., Charles et al. 1999a provide scenarios which could be interactively and linguistically played out in many different ways). That is, variation in decision-making styles has not been described in a way that makes its relation to actual spoken interaction easy to operationalise.

### 3.3 Tools and principles for framing analyses

#### 3.3.1 Framing meaning potential

This study concerns itself with interaction and representation, some of which is textualised, some of which is not textualised, but all of which can be framed in terms of different ways of speaking and interacting and the effect of these differences on whether decision-making is shared or unilateral. Therefore, modelling shared decision-making requires a way of framing the choices that affect its character. Such a frame needs to be able to relate the relevant domains of choice to each other and “bring a motivated order to the plethora of potential discriminations and terms” (Butt 2000a), including descriptive categories from the different disciplines that are drawn on in this study. If it can do those things then a framework is useful, even though it is not generally possible for any one framework to be perfect. Although a number of different research paradigms are drawn on in this thesis, the systemic functional linguistic (SFL) model of language is used to frame the analyses and relating the different perspectives and tools used to each other. Four key concepts are used, namely stratification, realization, metafunction and instantiation, each of which is discussed below.

#### 3.3.2 Stratification and realization

Stratification refers to the modelling of language as organised into different levels. Many linguistic models incorporate stratification, not just SFL. In SFL, the strata comprise: semantics - the system of meaning; lexicogrammar - the system of wording; and either phonology - the system of sound, or graphology – the system of writing. The strata are differentiated from each other according to order of abstraction, and related to each other in terms of realization (Matthiessen 1995, Halliday and Matthiessen 1999<sup>1</sup>). The central meaning of “realization” in linguistics

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<sup>1</sup> These concepts draw in particular on Firth’s “levels” (e.g., Firth 1957) and Hjelmslev’s “denotative semiotic” (Hjelmslev 1961 /1943), and are contemporary with Lamb’s (Lamb 1965). A stratificational approach is of course a key principle in linguistics more generally, dating back at least to Bloomfield (Bloomfield 1935) although there are many theoretical differences between approaches, especially in terms of what the principle of stratification is held to account for. In particular, in formal grammar (in

is to “make manifest” (Martin 1992). In a simplified view, lexicogrammar is realized by phonology/graphology and semantics by lexicogrammar. There is also a sense in which context is at least in part realized by language, and in some theories context is built into the model as the highest order of abstraction of an integrated meaning potential. An integrated model of language-in-context is the model used in this thesis.<sup>1</sup> Various authors stress that the realization relationship is not directional (or not unidirectional) (Halliday 1985, Martin 1992, Hasan 1995, 1999), although it does seem difficult for even the architects of the SFL approach not to fall into speaking and thinking about realization in this way, as Hasan points out (1999). In an attempt to clarify the “co-genetic” relationship between these levels of abstraction, it is helpful to consider the orders of abstraction as environments for each other to be brought into being (Halliday and Matthiessen 1999), such that:

- lexicogrammar is realized in phonology
- semantics is realized by the realization of lexicogrammar in phonology
- context is the environment in which semantics is realized.

The idea of language and context bringing each other into being is of course not restricted to SFL (e.g., Markova 1990a, Goodwin and Duranti 1992, Linell 1998, Malinowski 1935), but SFL provides a theoretical standpoint for integrating the

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contrast with SFL) the stratum of semantics is often limited to denotational meaning, with connotational meaning considered part of a separate component of pragmatics, implying a distinction between language and language-in-use. Additionally, formal linguistics usually does not model context of situation as a ‘level’ of semiotic abstraction. In SFL, on the other hand, it is considered helpful to model semantics as an “interface between grammatical resources and contextual systems outside language” (Matthiessen 1995: 33). These differing positions in fact reflect simultaneous disagreements about principles of stratal organisation, metafunctional organisation and the principle of the system-instance dialectic. Metafunctionally, SFL argues for a broader conception of semantics which includes interpersonal and textual meaning as well as ideational meaning. From the point of view of instantiation, SFL theorists argue against creating a separate component to deal with the meaning of an interaction in specific instances, since the resources speakers use to interpret particular instances of language are in great part systematic, and a systemic theory must deal with the relationship between the system and the instance (Halliday and Matthiessen 1999: 12). Although the SFL model is far from having resolved all problems and inconsistencies, its framework offers a productive way of relating shared decision-making, as a type of context of situation, to particular verbal practices that might constrain or enable it. For one example of work which integrates formal semantics with pragmatics in explaining the dynamic interpretation of language, see Kempson’s work (Kempson et al. 2001).

<sup>1</sup> Recent developments have expanded the meaning potential of the framework itself, to include descriptions of other modalities, and the integrated meaning potential of multi-modal “texts” (Kress and Leeuwen 1996)

description of language and context, and a number of technical tools for this purpose. See also Chouliaraki and Fairclough (1999) for a critique of this from a Critical Discourse Analysis perspective.

Clearly there is work to be done in clarifying the concept of realization. However, even with its current ambiguities, realization is a crucial principle in this study for relating the following descriptive categories:

- Categories of a very high order of abstraction, such as the practice of “shared decision-making.” This is considered a contextual category in the present thesis;
- Categories of a slightly lower order of abstraction, such as “representing treatments as a resource”, or “representing treatments as an obligation”. At this order of abstraction we also have “representing patients as agents of health care” vs “representing patients as passive consumers of health care”. These are considered semantic categories in the present thesis (sometimes called sociosemantic categories, following van Leeuwen 1995, 1996, to emphasise that they are broader than formal semantic categories);
- Categories of more manifest (though still abstract) practices such as making particular grammatical choices. These include practices such as
  - selecting modal Finite, as opposed to temporal Finite (e.g., “*According to our rules you should be on Bactrim*” from Consultation 37)
  - placing the patient in the grammatical role of Beneficiary and the drugs in the grammatical role of Agent (e.g., “*This can give you that resource*”, from Consultation 58)<sup>1</sup> rather than in some other configuration
  - choice of the lexical item *rules* (Consultation 37) cf. *resource* (Consultation 58)
  - use of the Circumstance of Angle, (“*according to our set of rules*”), and the fact that the projected angle includes the speaker but not necessarily the addressee, invoking medical authority.

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<sup>1</sup> But compare the same configuration of treatment as Agent, patient as Beneficiary, plus a negatively construed Goal: “And the antibiotic we give you to make it better, gives you? DIARRHOEA!!” (Also from Consult 58).

None of these lexicogrammatical choices in it directly realizes shared or unilateral decision-making. But in examining the complex negotiation of collaborative decision making it is important to identify how such lexicogrammatical choices may cluster together, realizing broad semantic oppositions between “treatment as a resource” and “treatment as an obligation”, as the examples above begin to show.

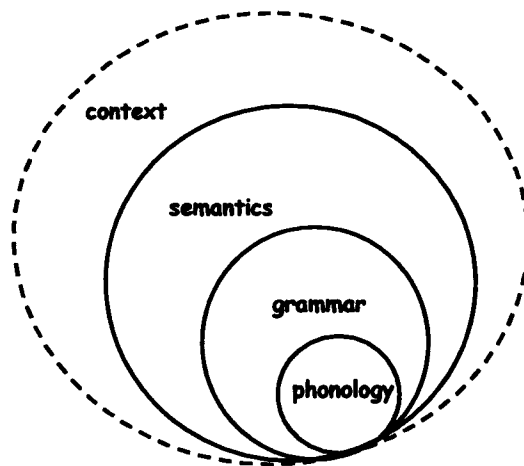


Figure 3.4 A stratified model of language and context (after Halliday and Matthiessen 1999)

Throughout the following chapters, but especially in chapter 4, I will draw on the notion of stratification in discussing the way in which social agency is construed in HIV decision-making. Essentially, the argument will be that there are a number of ways in which English organises resources for construing agency at the semantic level of abstraction, and in particular for construing semiotic agency, as distinct from agency in the material realm. Current semantic descriptions tend to replicate the description of resources for construing agency at the grammatical level of linguistic organisation and miss some of the additional organisation at the semantic level.

3.3.3 Metafunctions and functional diversification

The concept of metafunction refers to the highly generalised functions which language evolved to serve and which are evidenced in its organisation (Matthiessen 1995). According to SF theory, the three metafunctions are the ideational, the interpersonal and the textual, with a further division of the ideational into experiential and logical subtypes. The ideational function construes our experience, particularly through the system of transitivity. The interpersonal function enacts our roles and intersubjectivity by means of systems such as speech function and engagement. The textual function's role is a co-ordinating one: it presents ideational and interpersonal meanings as text in context, in terms of thematic prominence, newsworthiness, rhetorical transitions between messages and so on (Matthiessen 1995).

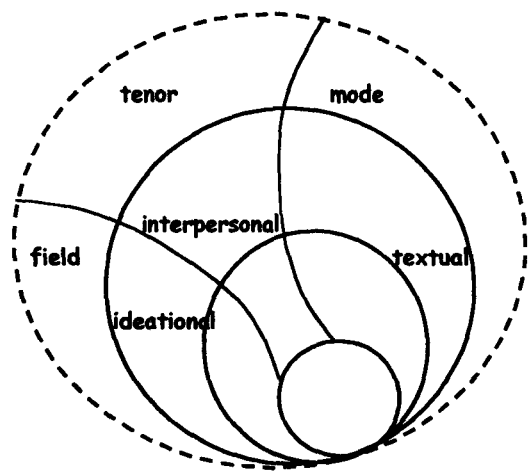


Figure 3.5 A stratified metafunctional view of language and context (after Matthiessen 1995: 19)

Figure 3.5 might be taken to suggest that the realization relationships in language and context only occur between levels of the same metafunction. This view may overstate the singularity of relationships between the functional organisation of language and of context. The view taken in this thesis is that the resources themselves are functionally organised but that their realization relationships are complex. The realization relationships are more properly considered as being between *configurations of context parameters* and *configurations of linguistic choices* (see Hasan 1999; Thompson 1999). The table below shows the principal SFL-oriented tools used in the analyses in this thesis. I have left the overall meaning space mapped by this diagram framed, but not partitioned. This is meant to

- emphasise that there is no one-to-one relation between grammatical choices and the realization of semantic categories, nor between the semantic choices and the realization of contexts;
- emphasise that at orders of abstraction higher than lexicogrammar, it is more helpful to speak of metafunctional perspectives on meaning-making resources, rather than of systems which serve one metafunction only<sup>1</sup>.

### 3.3.4 A brief description of some grammatical tools used in this thesis

Table 3.6 presents a schematic overview of the linguistically oriented tools used in this thesis. The table does not exhaust the categories for textual analysis that are offered in SFL or other approaches for analysing joint decision-making, but only to describe the resources most heavily drawn on in the thesis. Most of these tools are explained in the sections of the thesis where they are used, but a word about the clause level of analysis needs to be given here.

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<sup>1</sup> Compare Hasan's discussion of the 'permeability' between field, tenor and mode (see Hasan 1995, 1999, Thompson 1999). At the semantic level, Halliday and Matthiessen (1999:46) suggest that "the interaction base [i.e., interpersonal semantics] will include alternative 'projections' of the ideation base [i.e., the ideational semantics] to account for the relationship between speaker and addressee".



Table 3.6 Stratally and metafunctionally organised tools drawn on in my analyses

	Ideational	Interpersonal	Textual
	Field	Tenor	Mode
Context (turn, move, phase, text)	GSP/ Phase structure of context		
Semantics (message == clause or clause complex).	Social actor representation (van Leeuwen 1996)	Speech function	Message semantics (Hasan 1983, 1996)
	Cline of Dynamism (Hasan 1985a)		Identification
	Figure (Halliday & Matthiessen 1999)		Cohesion (Hasan 1984)
Lexicogrammar (clause)	Transitivity	Mood, Modality	Theme,

Each of the three metafunctions generates a strand of meaning. At clause level, these strands consist of the clusters of MOOD (interpersonal), TRANSITIVITY (ideational) and THEME (textual). These three strands of meaning are mapped onto each other in the clause as three distinct layers of structure (although it should be pointed out that the layers are simultaneous – there is no sense of hierarchy intended). This is in contrast to many other grammatical descriptions of the clause which only have only layer of structuring (Matthiessen 1995). One of the implications of the three-layer structuring is that features such as voice are conceptualised as different ways of conflating these three structures. For instance, the clause *Dr Evans gave me that script last week* is described in terms of its three

layers of structure in the figure below. A passive voice reconfiguration of this example appears in the subsequent figure. In the first example Subject is conflated with Actor (Dr Evans). In the second example Subject is conflated with Goal. Note too that in the second version “was given” is one ideational element, the Process, but it is two interpersonal elements (Finite + Predicator).

		Dr Evans	gave		me	that script	last week
Textual	THEME	Theme		Rheme			
Inter-personal	MOOD	Subject	Finite	Predicator	Complement	Complement	Adjunct
		Mood		Residue			
Ideational	TRANSITIVITY	Actor	Process		Beneficiary	Goal	Circumstance

Figure 3.6 Example of simultaneous grammatical functions and their conflation in structure: active voice

		<i>That script</i>	<i>was</i>	<i>given</i>	<i>to me</i>	<i>last week</i>	<i>by Dr Evans</i>
Textual	THEME	Theme	Rheme				
Inter-personal	MOOD	Subject	Finite	Predicator	Complement	Adjunct	Adjunct
		Mood	Residue				
Ideational	TRANSITIVITY	Goal	Process		Beneficiary	Circumstance	Actor

Figure 3.7 Example of reconfigured conflations in structure: passive voice

In discourse, there is a continual packaging and re-packaging of ideational, interpersonal and textual meaning together into one speech stream or written text. Research on interaction between doctors and patients requires analysis that can capture what is going on in any one of these strands of meaning at any one time, as well as the complex interplay between the three strands. This explains, for example, why researchers using an Interaction Process Analysis approach have recently recognised the need for parallel and sequential coding (e.g., Ford et al. 2000), but such approaches still underestimate the extent to which these strands are systematically and systemically organised through language (e.g., through the clause) as well as through interactive systems, especially turn-taking (see Schegloff 1996 for

a provocative account of the primacy of the turn; see Ong et al. (Ong et al. 1995) for a reasonably recent review of doctor-patient communication which discusses multifunctionality of language from a linguistically naïve point of view).

At other strata the three strands of meaning may not be kept as distinct, and within the SFL model the metafunctional organisation of strata other than lexicogrammar is certainly less fully understood, and less comprehensively formalized, at levels other than the clause (Halliday and Matthiessen 1999; Butt 2000a). There are also, of course, a variety of different and to some extent complementary perspectives of the model at all levels (Butt 2001).

At clause level, the SFL model of experiential structure posits a basic semantic distinction between processes, participants and circumstances, and then posits – for English at least – a much larger set of basic grammatical roles, which include items such Phenomenon, Senser, Carrier, Attribute, and a number of others, which have the same status as Actor and Goal and apply only when there is no Actor and/or Goal. These roles are specific to the type of process being construed, with the primary distinctions being between the construal of material processes (e.g., jump a fence, bend the truth, nail a job); mental processes (e.g., think something, be pleased by something) and relational processes (e.g., get sick, be invisible).

But the perspective is not simply a semantic in the sense of categorising types of processes into pre-linguistic categories (cf notional roles (Palmer 1994), or generalised (Foley and Valin 1984). This perspective on transitivity results from Halliday's observation that English has 'grammatical reactances' in systems such as tense and taxis that can be considered to mark a central distinction between the different process types – between the way that 'inner' and 'outer' experience is construed<sup>1</sup>. "The prototypical form of the 'outer' experience is that of actions and events: things happen, and people, or other actors, do things, or make them happen. The 'inner' experience is harder to sort out; but it is partly a kind of replay of the outer, recording it, reacting to it, reflecting on it, and partly a separate awareness of our states of being." (Halliday 1994: 106).

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<sup>1</sup> In this way it is similar to the approach taken by Fillmore (1968), in that both draw on Whorf's notion of reactances in the grammar, but Halliday's approach takes a language-based frame of reference rather than a situational one (Halliday and Matthiessen 1999).

Within this approach, the system of Agency/Voice is the system of experiential meaning at the grammatical level that construes a process as either brought about by an external cause (+ Agency, or “effective voice”) or internally brought about (- Agency, or “middle voice”). The feature +/-Agency here applies as a description of whether the construal conveys agency or not, rather than whether the construal identifies an agent. For instance, *You’ve changed the drugs* would be construed as +Agency, whereas *You’ve changed* (as in *I’d hardly recognise you*) would be construed as -Agency in a classical SF description. In both cases “you” is the Actor, but the type of action construes an effect outside the Actor in the first example, whereas in the second example the Actor is the Medium in which the change occurs.

Typically the feature +/-Agency applies only to material processes, and when it applies to other types of processes it is usually the case that there is no grammatical Agent until there are already two grammatical participants. For instance, according to Halliday and Matthiessen’s description, *The pharmacist told me to take these twice a day instead of twice a week* is middle voice (-Agentive) and the Actor “I” is the Medium. But in *I blame the pharmacist (i.e., for telling me I had to take these twice a week)* the equivalent clause is effective (+Agency).

### 3.3.5 Instantiation

The concept of *instantiation* posits a continuum between the overall meaning potential of a language and any instance of that language; the same kind of continuum applies between culture and situation, and between system and instance more generally (Matthiessen 1995: see 784; Halliday 1991). Thus at the narrow end of this continuum any instance of decision-making in HIV medicine can be interpreted as a unique interaction at a certain time with a particular agenda between particular individuals, and at the broad end of the continuum to be an instance of late modernity. Somewhere towards the middle of this continuum, an interaction can be seen as having a cluster of features that make us recognise it as an instance of medical decision-making. Slightly closer up, it might be possible to draw a distinction between shared decision-making and other forms.

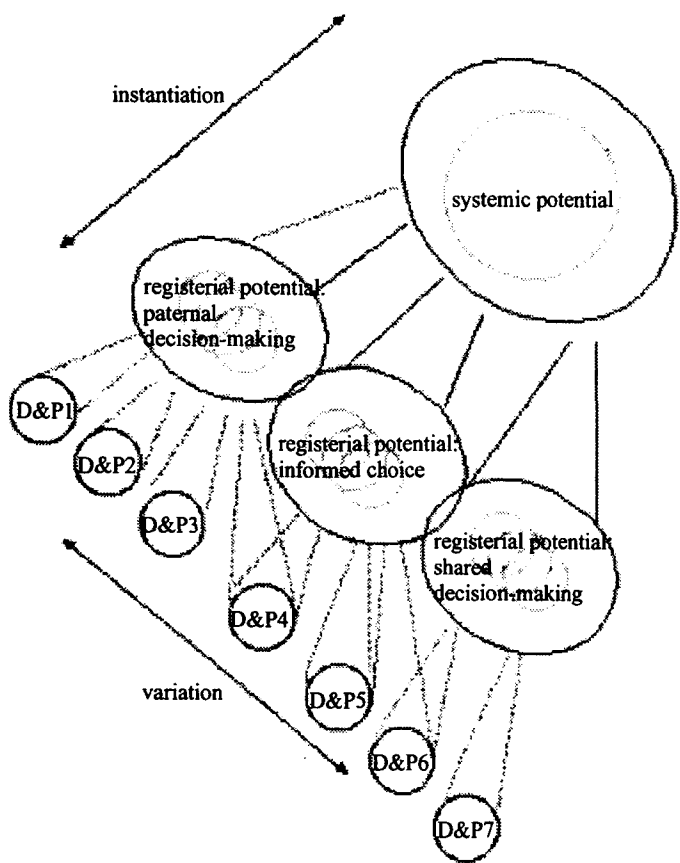


Figure 3.8 Shared Decision-Making and Instantiation, after Matthiessen (1993)

Figure 3.8 represents contextual variation in medical decision-making style in terms of instantiation, using the three-way contrast from Charles et al (1997, 1999a) of shared decision-making, paternalism and informed choice. In the light of the discussion in Chapter 2, I have not presented shared decision-making as lying between the other two types.

Halliday (1991) uses an analogy of weather and climate to explain the concept of instantiation. The weather on any day can be understood as an instance of a particular climate, where ‘weather’ and ‘climate’ are different observer perspectives on the same phenomenon (cf. Matthiessen 1995: 38). The relationship is

probabilistic, not directly causal – the climate does not determine the weather, but it is because we expect rain in Melbourne that we may be (pleasantly) surprised by sunshine. Like climates, language and the varieties within it change over time. For language, such change is a result of pressure from the communicative demands placed on it as the culture changes – and the demands of incorporating shared decision-making into healthcare are an example *par excellence* of such changes. The reciprocal also applies: as instances of shared decision-making occur, they perturb the system, changing the probability settings for medical decision-making as a register more generally. The variability that is abstracted into the three ‘styles’ is intended to be understood as continuous, and the styles as overlapping (cf. Charles et al 1999a, although different in the details).

Instantiation applies also to the relationship between meaning potential and actualisation at other levels of patterning in the language-context dialectic. For example, we may find that a particular text or corpus of decision-making instantiates the semantic category of obligation, while another text or corpus of texts instantiates the semantic category of preference.

Looking across disciplines, the notion of instantiation may help to relate a number of different conceptual frameworks for analysing shared decision-making. Sarangi and Roberts’s (1999) call for viewing the institutional order and interaction order as a dialectic is arguably concerned with instantiation. Here the question is whether discourse choices and patterns observed should be interpreted as a matter of participants’ orientation to specific roles and obligations associated with a particular institution, such as medicine, or a result of orienting to more general system of roles and obligations associated with a broader culture, however defined.

### **3.4 Interpreting data analyses - qualitative and quantitative aspects**

The study uses some rudimentary quantitative analyses of grammatical, semantic and contextual features (principally relative frequencies) to enhance what is essentially a hermeneutic approach of text interpretation. In chapters 5 and 6, an attempt is made

to examine ensembles of grammatical and other linguistic categories. These analyses are done in a quasi-quantitative manner: a category is selected for each message, but the analysis is intended to be interpreted in terms of scope or extent (mass), rather than frequency (count). In addition, I have categorised the observed treatment decision-making discussions, on the basis of the textual and interactive practices displayed in them, into unilateral and shared decision-making, and I have suggested how many of each type appear in the data. Whether relative frequencies are used to summarise analyses or not, the aim of grammatical analyses in this thesis is “to demonstrate [and interrogate] the connection between syntactic observations which we make about a text and the nature of the impact which that text has upon us” (Halliday 1973: 112) – and, where evidence is available, on other people.

The point of frequencies and indications of scope is to indicate the prominence of certain features. It is really only to support interpretive claims that a linguistic or interactional feature is foregrounded (or alternatively backgrounded) and thus significant in the creation and of a certain aspect of meaning, where significance is in terms of motivation. No statistical measure of the strength of association between a linguistic feature and an interpretive position – such as a claim that shared decision-making involves each interactant projecting the voice of the other – can establish this kind of significance: statistics can only display what Halliday calls prominence, even though the relation of significance is probably inherently statistical<sup>1</sup>. In this respect, linguistics is not very different from other fields, such as epidemiology, in which the importance of a statistical association depends on finding a motivated co-variation between two variables of concern, not merely on the size of a difference or the power of the study (Kerr et al. 1997). As Waitzkin (1991:53) points out, generations of philosophers, literary critics, and social scientists have used non-quantitative techniques to study discourses, and this type of scholarship has led to some of the most profound conclusions about what goes on in medicine, especially with regard to ideology, social control, and the nuances of communication in medical encounters. Although the legitimacy of claims on the basis of qualitative research must always be borne in mind, the doctrines of reproducibility and validity, which are often appealed

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<sup>1</sup> The distinction between foregrounding and prominence is technical but in my view problematic, and so I will not draw heavily on the term ‘foregrounding’.

to in such contexts, rely on consensus not 'truth'. They are liable to appropriation by ideology themselves, therefore "the best we can do is map ideology, but to do that we must of course pick a point of reference from which to begin and picking that initial point is a process that finally does not answer to 'validity'" (Waitzkin 1991: 290). Compare Giddens's (1984: 332 ff) comments about the ultimate failure of attempts to make a clear-cut division between qualitative and quantitative method.

### **3.5 Summary of this chapter**

No one framework can encompass all relevant others, and the one described here is intended to be 'sensitising' rather than 'definitive', providing 'directions along which to look' rather than 'prescriptions of what to see' (Blumer 1969: 148, quoted in Rampton et al. 2002: 387). There is always a need to stay aware of potential bias towards those aspects of meaning which are textualised, i.e., capturable on tape or page (Hak 1999), but it is certainly possible to work in the kind of frame identified here and attend to the non-textualised – van Leeuwen's work on representing social actors and action (1995, 1996), which will be examined in Chapter 4, is a case in point. It is to that chapter that I now turn, and to the question of how social theory and linguistics might be brought together to help clarify the role of agency in HIV treatment decision-making.