

7

Study conclusions and implications for practice and research

7.1 Summarising the findings of this study

As pointed out in chapters 1 and 2 there is a considerable literature on shared decision making in medicine, but there are still a number of problems which make it difficult to interpret this research and integrate it into practice (Kravitz and Melnikow 2001, Braddock et al. 1999, Gattellari et al. 2001). What appears to be a well covered research field in fact has many unanswered questions and prematurely answered questions. In particular there has been a tendency to treat doctor-patient interaction primarily as behaviour, but not as language. Clearly it is both, and its study must be able to relate descriptions of contextual behaviour to motivated, functional descriptions of language in interaction.

From this perspective, this study set out to i) describe the degree of shared decision making within a corpus of consultations between people living with HIV and their doctors, and ii) to identify key discursive and linguistic practices used by doctors and patients and to explore the role of such practices in facilitating or impeding shared decision making. This chapter summarises the findings of the study with respect to decision making practice and discursive practice, and outlines the limitations of the study. The chapter then addresses some implications for research and practice, in terms of what we are aiming for in modelling shared decision

making, and how feasible such aims might be. I begin with a summary of the distribution of shared decision making across the corpus.

The distribution of shared decision making HIV medicine

As foreshadowed in early chapters, this thesis has taken “shared decision making” to refer to a range of the more collaborative ways in which doctors and patients engage in making and reviewing decisions, with the aim of establishing or maintaining a joint position about treatment. Decision-making itself is understood in this thesis as an incremental, recursive and elusive process (cf. Boden 1994, Atkinson 1995) which may be foregrounded in explicit episodes or may be implicit in ‘other work’ within medical interactions, and most of the interactive data analysed in the thesis have required attention to both explicit and implied decisions, part-decisions and non-decisions.

Across the corpus of 74 consultations studied, the majority of decisions were made in a collaborative manner considered to instantiate shared decision making. Comparing decisions about antiviral combination therapy (HAART) with the perhaps more routine treatment decisions that might be made in any GP practice, it was found that decisions about HAART were *less likely* to be shared than non-HAART decisions (see chapter 3). Furthermore, doctors in the present corpus were more likely to make unilateral decisions about HAART than about other treatments. Within decision making about HAART, patients made unilateral decisions not to initiate and were able to influence doctors about agreeing not to change treatment. Doctors made unilateral decisions to change treatment, but no patients in the study were able to unilaterally change their treatment. Patient-initiated attempts to change treatment were either reconstrued ultimately as the doctor’s recommendation (e.g., Neil and AZT in Consultation 29-31) or required strategic moves towards a hard-won, incrementally achieved shared decision making (e.g., Philip with ddC/ ddI in Consultation 3).

These findings emphasise the existence of contextual constraints on opportunities for shared decision making (cf. Charles et al. 1999a), but they also suggest that the practice of shared decision making, at least in certain parts of the

medical community, may be higher and better established than research has indicated, especially the research that focusses on one-off interactions between doctors and patients.

Modelling shared decision making as the configuration of multiple contextual parameters

One key reason why collaborative decision making was found to be common in this corpus is that shared decision making was characterised, as shown in chapter 5, in terms of a flexible set of contextual configurations, and in particular in terms of the Tenor relations established and/or evident in the consultation. The key criteria for these were the construal of reciprocating agentive roles for doctors and patients, which shifted with phases in the consultation, and in particular which positioned patients as having an agentive role in specialised, reflection-based fields of discourse. As suggested in chapter 5, such an approach to characterising shared decision making makes it possible for long, short, routine, novel, high-stake and not so high-stake types of decisions to be brought into the frame of consideration with respect to shared decision making, as called for by Gattellari et al. (2001).

This approach stresses that decision-making styles, like decisions themselves, are always incrementally achieved through interaction (cf. Maynard 1991, Atkinson 1995) and the findings of this study point to doctors' and patients' skilful, expert deployment of a wide range of discursive resources every time they achieve shared decision-making (cf. Atkinson 1999, S.Candlin 2002). This view of how shared decision-making is achieved raises some questions about the advisability of models of decision-making which specify a particular step in the process for "exploring patients' role preferences" or equivalent behaviours (Towle and Godolphin 1999, Elwyn, Edwards, Gwyn and Grol 1999, Brown et al. in press). As Elwyn and colleagues (Elwyn et al. 2001) point out in their study of the implementation of shared decision-making practice, this step and other "exploration" steps are often found wanting in actual practice, even among those intent to share decisions. They go on to characterise such steps as the "unchallenged mantras of communication skills training" which may need to be de-bunked. The findings and theoretical

underpinnings of the present thesis tend to support this view, but an alternative way of specifying and evaluating shared decision-making is still required.

The discourse analytic approach presented here suggests that there are important covert patterns within the linguistic and interactive choices that doctors use in realizing any or all of the 'steps' in decision-making which act either as a covert invitation for patients to participate in treatment decisions, or as a sign that participation is not welcome. These messages are constantly being sent, responded to, elaborated, adjusted, and readjusted. If they are negative, they may easily outweigh any upfront statement of a doctor's receptiveness to participation. Equally, there are latent patterns in patients' linguistic and interactive choices which have similar functions. Facilitating shared decision-making is a matter of constant alignment and realignment between doctors and patients in terms of this latent patterning, as well as more overt explicit displays of mutual engagement and statements of position.

Decision-making and generic structure

This does not mean that treatment decision-making (or medical interaction more generally) does not have a particular generic structure that distinguishes it from ordinary conversation, or that it is not helpful to describe such structures in terms of stages or phases, and evaluate the effects of omitting or resequencing elements or phases. This tension between prescribing too rigid a structure for medical consultations and uncritically gauging them against the norms of everyday conversation (whatever that is taken to be) has recently been carefully discussed by ten Have (2001) who takes a similar view to the one presented here.

The chief conclusion of the thesis in this regard is that it is important that some elements of the decision-making are not "process shared" (Hasan 1985a). Brown et al. (in press) make a similar point, but researchers in this field tend to present or imply a view that maximising process sharing across all stages and aspects of the decision-making episodes is the ideal way of achieving shared decision-making (Robinson and Thompson 2001: 135, Skelton et al. 2002). In this thesis, it is considered very important for doctors to declare their treatment recommendations in

a way that makes it clear that the patient is not represented as sharing such a view until they have independently indicated that they do share it. The thesis argues that this is facilitated by a model of decision-making which incorporates distinct phases that separate the declaration of recommendations and/or preferences from the Enunciation of treatment decisions, and which model the patient as author, animator and principal (in Goffman's sense) of the decision Enunciation phase. It will then be important to evaluate whether such a model is recognised by practitioners as valuable and feasible, or whether this is another 'communication skill mantra'.

Agency and shared decision-making

Chief among the discursive resources involved in latent invitations and offers for patients to participate in shared decision-making in HIV medicine, and in the enacting of such participation is the construal of agency through verbal interaction. As we saw in chapters 4, 5, and 6, the construction of agency in medical decision-making is complex and variable. With a multidimensional approach it is possible to describe the types the different models of agency being mobilised in HIV medicine, and to identify many of the discursive resources drawn on by doctors and patients. This makes it possible to identify ways in which patients' participation in collaborative decision-making may be acknowledged, foregrounded, and encouraged – or conversely may be downplayed and impeded – which as analysts we may otherwise have missed.

Bringing a more complex model of agency to our analysis of these issues and types of data also allows us to problematise the way in which agency is conceived by patients and doctors, not just identify when and where agency is enacted or at risk as meaning potential. For instance, it is possible that readers might construe the GP Karen, discussed in chapter 6, as a persuasive dynamic figure who pushes her patient Joan into taking antivirals. Such readers might support their interpretation with a kind of linguistic analysis of agency which privileges a concept of agency as unfettered individual action. On the other hand it is possible to argue, as I have done in this thesis, that there are other models of agency available within the culture of late modernity in general, and the discourses of HIV medicine in particular, which

view agency as inherently mediated by social interaction (cf. Vygotsky 1978, Wertsch 1990) and as always structurally constrained and facilitated (cf. Giddens 1984, Bourdieu 1991, Bernstein 1996). From this perspective Karen's agentivity may be understood as a resource for Joan's agentivity.

Having examined, in chapters 1, 4, 5 and 6, how patients such as Victor, Neil, Michael, Joan, Brian, Philip, and Stephen display (at least some of the time) such a complex, mutually dependent agency, which also involves institutional policies, theories, test results and other abstract semiotic phenomena as agents, it is possible to reconsider the contrastive quotes used by Race and colleagues to demonstrate the role of agency in distinguishing conventional and complementary therapies. As we saw in chapter 4, the HIV+ research respondent Martin quoted in Race et al. (1997) represented himself in a particular kind of agentive role with respect to complementary therapies (*"I'm on my own little vitamin trip..."*). In this way Martin construes himself as highly autonomous and independent in his use of complementary therapies. This seems to correlate with the Race et al.'s (1997) interpretation of how Martin is positioning himself and his rhetorical use of this response in terms of the study interview. From a more critical point of view however, we might go on to problematise Martin's model of detached, completely differentiated agency, in which the "institution" does not constrain, but nor does it enable. We might also want to problematise a discourse analytic approach which naturalises such a model of agency. Relevant here is Ahearn's (2001:4) caution that researchers must reflect carefully on their conceptions of agency since these have implications for the understanding of personhood, causality, action, and intention.

Other ways of indicating that a patient has a legitimate claim to a view and opportunity to present it of course exist. For instance, Peräkylä (2002) suggests that in the context of making diagnoses, one thing a doctor can do to encourage patient participation is to indicate to the patient some of their evidential grounds for pursuing a particular diagnosis, and we can easily interpolate to providing evidential grounds for treatment recommendations. According to Peräkylä this works by indirectly suggesting that it is relevant for the patient to speak at such a point, but as he demonstrates, in most cases when patients do respond with extended discussion of the diagnosis they do not address the evidential grounds presented – that is, they

respond to but do not debate the reasons for holding a certain view and only occasionally make it clear that they hold a different view. Perhaps patients are more likely to do this where they are more directly represented and modelled as semiotic agents in the process of medical decision-making. The present study provides some support for this hypothesis, since patients were found to interrogate the reasons for holding a certain view about treatment options, the status of claims (e.g., that's a theory right?) and the comprehensiveness of inferencing and recommendations, and on the interpretation of tests.

Crucially, the approach outlined here raises this possibility of different conceptions of agency, and different ways of configuring and realizing shared decision-making. It attempts to warrant its claims and evaluations of shared decision-making through the "thick description" (Geertz 1973, Ryle 1971) of how agency and related areas of meaning potential are actualised, mobilised and aligned in practice. The idea of thick description entails the analyst revisiting the same materials and adding "layers" of description (Duranti 1997: 37), as I have attempted to do here. A thick description is necessary because collaborative decision-making is a complex, layered social process, the understanding of which is always interpretative. Ryle's famous example (chapter 37, 1971) discussed how a thin description of the opening and shutting of eyelids might fail to contrast a twitch from a wink, and this reminds us that shared decision-making cannot be reduced to steps, phases, semantic tropes, or latent grammatical patterning, but that all these are important in an integrated picture.

A key aim of providing a "thick description" in the present study has been to make the connections between instances of interaction and descriptions of styles of decision-making available for communities of patients, practitioners, and researchers to scrutinise (cf. Coupland 2001, Sarangi and Candlin 2001, Chouliaraki and Fairclough 1999). Although it is acknowledged that theses are not frequently read by such groups, the arguments and data presented here constitute the basis for more accessible publications and forums of discussion.

Dialogue, dialogism and shared decision-making

As part of the exploration of agency and alignment between doctors and patients in this thesis, it was found that one of the most important discursive resources contributing to shared decision-making was the mutual projection by doctors and patients of each other's voice and view. That is, the representation of dialogue, both actual and unrealis, within real-time dialogue between doctors and patients, is a key resource for negotiating alignment about treatment options and the discourses by which these are framed. This is similar to Aronsson and Sätterlund-Larsson's (1987) point that medical consultations entail "thinking out loud" as a collaborative activity between the main thinker (in their study this was the doctor) and the commenter (the patient)¹. Under this view, the picture provided by this thesis is that under certain conditions, when the doctor projects the voice of the patient, this functions to re-distribute the roles of thinker and commentator. A subsidiary claim is that these conditions are largely to do with the sociosemantic representation of the patient as a social actor within a network of social actors. In specialised, reflection-based discourses such as HIV medicine, the role of projection builds up a network of relationships between inanimate symbol sources such as viral load tests, in addition to the social relationships it invokes. It should be stressed that collaborative thinking and abstract tools are not merely mediational means which are "somehow secondary or ancillary to an already existing form of action" (Wertsch 1990: 69) but which "alter the entire flow and structure of mental functions" (Vygotsky 1981: p. 137, quoted in Wertsch 1990: 69).

If Vygotsky is right and thinking and deciding are interpsychological and dialogic at base, his theories would seem to offer a potentially fruitful alternative to more mainstream psychological approaches for developing models of decision-making in medicine. As Markova (1990a) points out, drawing on these theories and also on scholars such as Mead, Baldwin, and von Humboldt, it is through the mutual exchange of ideas, i.e., through speech, that human beings stimulate each other. Markova's view is that is most profoundly true of the ontogenetic development of the person, in that the child can only have a monologue with him- or herself only

¹ Cf. the *et cetera* principle (Garfinkel 1967, Cicourel 1973)

after he or she has developed the ability of holding a dialogue with others (Markova 1990a: 10), but it is also true of the logogenetic ‘making up one’s mind’ that occurs in interactive situations such as medical consultations, in the sense that “one must always test one’s own ideas against those of other human beings to see where one is going” (Markova 1990a: 7, after von Humboldt 1836-9).

Shared decision-making and the discursive nature of equipoise

Although these findings cannot be generalised beyond the present study, they are of interest to the general debate about why and when shared decision-making is possible. Various authors have argued that it is only where a state of equipoise is achieved and thus there is truly a choice of treatment options, that is ethical or feasible to invite patients to participate in deciding which treatment option to pursue (Elwyn, Edwards, Gwyn and Grol 1999, Gwyn and Elwyn 1999, Brown et al. in press, Charles et al 1999a, Thomasma 1983). One observation which lends support to the hypothesised relation between equipoise and sharing treatment decisions is that doctors in the study constructed prophylactic antibiotics (especially Bactrim) as unequivocally important, e.g., Tony, in Consultation 48, turn 109 getting Brian to agree that “*the Bactrim’s vital though isn’t it?*” Doctors even displayed alarm when a patient appeared to have “broken ranks” with regard to taking Bactrim, such as Trevor’s assertive declaration about Bactrim below, made in a manner which was not displayed when patients disclosed lack of adherence to antiviral medications (e.g., elsewhere in Consultation 37):

37_71 D I mean, that- the point is about- the point is about PCP, that we know that the risk g-goes shooting r- upwards once you drop below two hundred, right? So, there’s no- according to our- OUR set of rules... you should be on Bactrim.

By contrast, when the doctor Karen summarises her position on recommending antiviral treatment, this may be interpreted as a succinct but implicit statement of the relationship between equipoise (in her professional discourse community) and the increasing appropriateness of involving patients in decision-making:

- 59_60 D Our- the sort of way that we run on this is, if you've got a rate of a hundred thousand, I'm going to sit on your head and make you take treatment, right?
- 59_61 P Okay.
- 59_62 D If you've got a rate of less than ten thousand, I'm going to say, it's a good idea, but you think about it. And between ten and a hundred, or maybe even fifty, y'know, or between ten and a hundred I'd say, increasingly it's a good idea.

From the perspective of the medical community, and from the individual clinician's certainty about benefit/ harm ratio, HAART exemplifies the highly uncertain end of the spectrum. During the period in which the consultations in the study took place these treatments were often still experimental, survival data was only available for a few combinations, and there were many different policies being debated among experts, which were largely based on rhetorical strategies, ranging from "hit early hit hard" with four antiviral agents, through to the "keep the proteases up your sleeve" approach. From this perspective we might have expected that treatment decisions about antiviral treatments might have been more likely to be shared than non-HAART decisions, most of which involved better established treatments than HAART, but this was only clear in the case of Bactrim. At the same time, HAART exemplifies a treatment regimen with great potential for significant, life-extending and life-enhancing benefit where little had existed before. From this second perspective then it is not surprising that doctors in this study had strong views on the best HAART options, and attempted to persuade patients accordingly, even though clinicians' views differed from each other.

Taking both perspectives into account, these findings suggest that "equipoise" appears closely related to doctors' discourse about their decision-making practices (Gwyn and Elwyn 1999, Elwyn et al. 2001), but it does not determine when shared decision-making is actually undertaken by doctors. More generally, equipoise is one example of an area of meaning potential which may be construed by researchers as an independent factor in the context, that is, a clinical factor which independently determines whether it is appropriate for a decision to be shared. It is argued in this thesis (especially in chapter 5) that such factors are only ever partially independent of the linguistic and interactive practices through which they are interactively

negotiated with patients. This is an area where further reflection is needed about what is meant by equipoise, what is gained and what is risked in detailed discussion of equipoise with patients. In particular this requires more data on the ways in which this highly complex area of meaning potential is realized in practice by doctors and patients in different fields of medicine.

7.2 Study limitations and challenges for future research

The study described in this thesis offers a number of new insights into the nature of shared decision-making and into ways of characterising decision-making as discourse practice. There are of course many limitations to the study and the way in which it can be drawn on.

As stressed in the early chapters, considerable attention has been given to specifying what is meant by shared decision-making, what is meant by agency, and how any one instance of HIV decision-making can be related to these frameworks. However, it was not possible to fully specify recognition or realization details, therefore the study lacks some repeatability and evaluability. It may not be possible to get to the level of repeatability achievable for some types of discourse analytic studies, including corpus-analytic approaches, or for the those studies which employ an “Interaction Process” method, following Bales (1950), Roter (1991), Ong et al. (1998) and others. Nor was it possible to conduct systematic grammatical analyses of all the consultations in the corpus, for reasons of time and space. Largely these shortcomings are a function of the necessity for including local contrasts (e.g., the way in which Joan’s vulnerable identity becomes a resource for her construction as agentive in the process of deciding about treatment and in the treating itself (Consultations 58 and 59), including the need to present a logogenetic account of a number of decisions.

It should be possible to relate the descriptions of agency generated by the network presented in chapter 6, to the contextual parameters that distinguish shared decision-making from unilateral decision-making as described in chapter 5. Although it is beyond the scope of this thesis to do this in an exhaustive way, the interactions I

have described in the thesis provide an illustration of how this might be done, and some of the limitations and difficulties of doing so, and these issues are being addressed in ongoing research. It might be necessary to elaborate or customise the published context networks for the context of HIV decision-making to make a clearer picture of the links, but the approach has promise for the examination and evaluation of shared decision-making in practice.

There are a number of additional technical shortcomings with the networked approach to agency presented in the thesis, but at the same time the analyses are provocative for a theory, such as SFL which stresses the contextually responsive modelling of meaning making. The findings and approach of this study tie in with recent work in SFL elaborating Field, Tenor, and Mode as tools for empirical research (Hasan 1999, Butt 2000b). They also echo recent concerns with the way that the Interpersonal contextual dimension of Tenor is particularly sensitive to small changes in the Experiential grammar and semantics (Thompson 1999, Heyvaert 2001).

Despite drawing on dimensions of meaning, the approach presented in the thesis was necessarily focussed on representational meaning, within the semiotic modality of language. There are indications for examining other modalities beyond spoken language. In particular, it would be important for future research to give more attention to visual and multi-modal decision aids, but these must not be seen as an alternative to studying verbal communication in medicine: integrated analytical frameworks are required in order to deal with the integrated meanings made (e.g., Kress and van Leeuwen 1996, Scollon 1998).

Most importantly, the explanatory value of studies like the one presented in this thesis would be greatly enhanced if the methods demonstrated here could be combined with patient and doctor reflection (e.g., through narrative/ semi-structured exit interviews). In this way it might be possible to calibrate what Gattellari et al. (2001) call patients' "perceived role" in decision-making, with the specific discursive practices through which such decision-making episodes were realised. The results of such studies would provide a much better sense of what shared decision-making means to different groups within the discourse community involved in its practice. This would be the most important next step in a research program aimed at

developing more comprehensive measures of characterising collaborative decision-making (Gattellari et al. 2001, cf. Moatti and Souteyrand 2000, Race et al. 2001, Dowsett and Davis 1998).

Clarifying goals, clarifying models

As pointed out in chapter 2, it is not theoretically or empirically sustainable to model shared decision-making as positioned “between” unilateral decision-making made by one party, and unilateral decision-making made by the other. The discussion of HIV decision-making practices throughout the thesis confirms this view. In order to discard the notion that agency in health care is essentially oppositional, zero-sum-game agency, and focus on understanding and fostering the kind of complex negotiation and enactment of agentive roles that characterise this corpus, we need to see that oppositional agency, along with an essentially monologic view of language and thought, underpins spectrum models of decision-making style, such as Charles et al. (1997, 1999a,b).

There are empirical puzzles which may be illuminated by approaching agency and shared decision-making as complex, contextually sensitive, and interactionally achieved in the manner outlined in this thesis. For instance, Gattellari et al. (2001) found that, irrespective of patients’ preferred role in decision-making, the role that patients perceived themselves as playing was a significant and independent predictor of their satisfaction with the consultation overall, and with the amount of information and emotional support they received from their doctor. In their study, patients were most satisfied with a shared role, whether or not they had indicated a preference for a shared role. Patients who reported that they either made the decision themselves or that the doctor exclusively made the decision were least satisfied. Role “mismatch” (i.e., difference between their preference and their perceived role) was not significant predictor of satisfaction. While Gattellari et al. are probably right to interpret their study as evidence that encouraging shared decision may be the safest general approach, their results are consistent with the claim made in this thesis (cf. Elwyn, Edwards and Kinnersley 1999) that patients may not typically come with fixed preferences about decision-making style that are independent of the contexts of

decision-making, the details of what needs to be decided, and the interactive discursive construction of these phenomena (cf. Maynard 1991). To treat them as if they do, in medical practice or in research, will inevitably lead to problematic relationships and problematic data.

The potential of this research for enhancing clinical interaction

What evidence is there that the model presented in this thesis has practical relevance for enhancing shared decision-making? Research such as that of Gattellari and colleagues (2001), cited above, and Street and Voigt (1997), discussed earlier in the thesis, provide modest evidence for a rather strong claim, that patients directly benefit from a sense of participation in and control over treatment decisions.

Research such as that of Fallowfield and colleagues (Fallowfield et al. 2002, cf. Brown 2003, Elwyn et al. 2001) has indicated that clinicians are interested in developing skills in this area, and that training can provide sustainable changes in doctors' behaviours according to specific models of shared or collaborative decision-making. Incorporating a somewhat more linguistic/ discursive approach², Brown (2003) has shown that communication training can have a positive impact on oncologists' communication about clinical trials across behaviours associated with shared decision-making.

After training, doctors' behaviour incorporated a greater number of the features of shared decision-making, and this included more explicitly offering choices of treatment than they had done before training; doctors also skipped fewer phases of the consultation. In particular doctors included and elaborated the Enactment phase, discussing in more detail how a chosen treatment plan would be implemented.

² The training program, designed to provide oncologists with communication skills to assist them in seeking informed consent in an ethical manner, used a model of strategies for achieving collaborative decision making similar to the one presented in this thesis, and to which I contributed (see Brown et al. in press). In particular, the approach emphasises the importance of using language that portrays patients as active in the process of deciding about their health care and which avoids coercive construals of options. It also emphasises the importance of sequence in the interaction, and of appropriate shifts in who takes the lead role from phase to phase, according to patient preferences. A pre-post intervention method of evaluation was used.

Training produced an increase in the extent to which essential clinical information was given, which includes discussing the 'no treatment' option, discussing the prognoses of both 'no treatment' option and specific treatment options. There was no change to doctors' provision of 'essential ethical information', e.g., declaring or discussing equipoise (cf. Elwyn et al. 2001). On a separate measure of coercion, doctors were found to discuss treatment options in a less coercive manner after training. This measure largely reflects changes in framing practices, including the use of both positive and negative representations of prognoses etc., and the increased use of numerical descriptions of risk. What has not been tested, as far as I have been able to ascertain, is whether specific interventions can influence the extent to which and ways in which doctors construe patients as agentive, and whether this in turn fosters patients' adoption of an active role in collaborative decision-making. Nor have there been any specific interventions along these principles targetted at patients, HIV community groups, or stakeholders not acting in a professional capacity.

What we do know, however, is that when students are given a metadiscourse for describing the kinds of linguistic and interactive features discussed in this thesis, their ability to identify and manipulate these features as producers and consumers of text and interaction increases, even when they are as young as 10 or 11 (Williams 2000). Children in Williams and his colleagues' study were able to describe and critique social asymmetries in literary works and relate these to transitivity patterns in texts, and they were also able to identify important semantic features which transitivity categories failed to net in, such as modes of address.

While the teaching of grammar as an essential resource for literacy (in the broadest sense of the term) is a controversial topic in education generally, it is virtually a non-topic in medical education. Some influential figures have argued the need for language studies (as distinct from communication skills training) should be part of the foundational curriculum in medication education, criticising the lack of attention given to language and interaction as akin to giving students a stethoscope without teaching them the physiology of heart sounds and how to and interpret them (Cassell 1985).

Cassell (1985: 45), who references Halliday and other linguists in his books on doctor-patient communication, points out:

Because language can be used in diverse ways, an individual's language use does more than describe worlds real and imaginary; it characterizes the language user as well...You are always trying to find out how speakers view themselves in relation to what they are speaking about - as well as what they are speaking.

Cassell's view echoes the view described in this thesis that many of these meanings are available through latent patterning in language, and some of these are not things that can be ascertained by asking patients about a proposition. Patients of course can nominate how much they feel they have participated in making a treatment decision, but we do not have good evidence that people's gradings of participation are well calibrated, just as one person's "terrible pain" may be another person's "slight discomfort" (cf. Cassell 1985), and these calibrations may vary from occasion to occasion and from telling to telling. Certainly patients and doctors are in a position to describe the level of participation they want and the level of participation they feel they achieved, but they may not be in a position to describe the mechanics of how they come to such a perception, though as outlined above, the availability of a metadiscourse for such descriptions is crucial. Education and professional development, and resources for the development of interaction skills among patient communities, including decision aids, will increase the chances of proving valuable if they incorporate attention to the details of diverse ways in which language can be used, and the differences these make to the types of worlds, relationships and social processes construed.

Even without specific interventions to change practice, it must be recognised that shared decision-making is a new way of meaning not just a new way of making the same meanings that were made within a paternalistic discourse of medicine³. Change in forms of social action and forms of language are always two perspectives on the one process (Halliday 1984). Professional responsibility implies that doctors

³ and before that within a discourse that was consensual but much less accessible for the majority (Rosenberg 1979)

should be involved in reflecting on and guiding these changes at the level of the instance, in scaffolding shared decision-making for patients. Doctors and medical educators, and arguably health policy makers and stakeholder groups, should be involved in some way in directing such changes at the level of the system, or the phylogenetic perspective. Political reality, and current evidence, suggests that patients are however often the active ones in scaffolding the process for doctors.

The feasibility of shared decision-making

An important question raised by a number of commentators is the feasibility of achieving a situation in which medical decision-making routinely shared with patients, to the extent that patients are happy to participate (Coulter 1997, Coulter et al. 1999, Elwyn, Edwards, Gwyn and Grol 1999). As well as asking whether particular models of decision-making or types of information or decision aid can be generally available, it is worth asking whether patients are ever able to make decisions to treat or not treat, or whether, alternatively, they are constrained to make them by the system. The answer is, of course, both. An important limitation is that the HIV subject is produced by the somaticising and technologising of risk (and benefit) that is central to modern medicine and modernity in general (Flowers 2001, Giddens 1991, Candlin and Candlin 2002). The identity of a patient with a high viral load, in particular, is a *produced* identity (cf. Race et al. 2001). It may be a patient's choice to take up such an identity and mobilise it to select a particular treatment, much as it may be an immigrant family's "choice", despite their concerns about integration, to live in a suburb where people share their language and culture, even though it is at the same time social structures which make this the only viable choice, as Giddens (1984) argues. It is certainly possible to critique the use of the language of choice in medicine (Illich 1975), but that would not be useful in the HIV context, because modern medicine is extremely valuable to PLWHA even in its current flawed state, in contrast with Illich's view of medicine as a whole as fundamentally malignant. Within a medical system, then, the best that can be hoped for, from a patient-community point of view, is participation in decisions, both at the policy level and in clinical settings.

The challenge for those who would enhance patient participation is to enhance shared decision-making at the coalface as we have been discussing, and to integrate this with the social positioning of patients within the health system. In HIV medicine, the capacity to treat the infection is real but incomplete. There is thus a continuing need to focus on clinical communication and patient education, across a range of issues from treatment decision-making, to adherence, to the relationship between virological control and preventing transmission (Davis 2002) while at the same time avoiding the overmedicalisation of people's lives (Kippax 1999). As increased access to antiretroviral drugs and treatments for opportunistic infections begin to change what it means to be "living with HIV" in developing countries there is also a very great need to consider how the benefits of treatment can best be extended to those affected by HIV in these regions (Kitahata et al. 2002). It will be important consider how the collaborative decision-making that such treatments require may be informed by existing models of shared decision-making, and how experiences outside the western world might enhance our understanding of the different ways in which decision-making may be shared.

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Appendices

For privacy and confidentiality reasons the following appendices have been omitted from this thesis.

Appendix 1: Selected aspects of the experiential grammatical analysis for key transcripts (pp. 425-520)

Appendix 2: Selected aspects of the interpersonal grammatical analysis for key transcripts (pp. 521-530)

Appendix 3: Degree and type of fusion between patients (P) and their viral load (VL) (pp. 531-532)

Due to copyright laws, the following appendix has been omitted from this thesis.

Appendix 4: Published article (pp. 533-556)

The citation for the article included in the appendix is given below. Please refer to the link for the abstract details.

Moore, Alison, Candlin, Christopher N. & Plum, Guenter A. (2001). Making sense of HIV-related viral load: one expert or two?. *Culture, health & sexuality*, 3(4), 429-450.

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