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The role of patients' meta-preferences in the design and evaluation of decision support systems

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Abstract

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The arrival of new analysis-based decision technologies will necessitate a profound rethinking both of the nature of the patient–doctor relationship and of the way aids and support systems designed to improve decision-making within that relationship are designed and evaluated. One-dimensional typologies of the traditional ‘paternalist/shared/informed’ sort do not provide the complexity called for by the heterogeneity of patient’s ‘meta-preferences’ regarding their relationship with a doctor on the one hand and regarding the analytical level of judgement and decision-making on the other. A multidimensional matrix embodying this distinction is proposed as a framework of the minimal complexity required for the design and evaluation of the full range of decision aids and decision modes. Essentially aids should be conceived of and evaluated *cell-specifically* and the search for universally satisfactory decision support systems abandoned. ‘shared’ and ‘informed’ are best interpreted as attributes which may or not be in line with a patient’s meta-preferences. Future research should focus on the higher level goal of *better* decision-making, a goal that will need to respect and reflect these meta-preferences.

Introduction

The arrival of new decision technologies will necessitate a profound rethinking both of the nature of the patient–doctor relationship and of the way aids and support systems designed to improve decision-making within that relationship are designed and evaluated. The development of decision-analysis based programmes such as CODA¹ DARTS^{2,3} PORTAL and ALCHEMIST⁴ and WEDS⁵ points to the growing necessity to distinguish the nature of the doctor–patient relationship from the modes of judgment and decision-making employed within that relationship. Implicitly one-dimensional typologies of the traditional ‘paternalist/shared/

informed’⁶ sort do not separate these two dimensions, nor do they provide the complexity called for by the heterogeneity of patient’s ‘meta-preferences’ regarding each. A multidimensional matrix embodying this distinction is proposed as a framework of the minimal complexity required for the design and evaluation of the full range of decision aids and decision modes. Essentially aids should be conceived of and evaluated *cell-specifically* and the search for universally satisfactory decision support systems abandoned. The decision process which emerges when patient’s meta-preferences regarding relationship model and decision mode are fulfilled may be very different from that which would constitute ‘shared’ or ‘informed’

decision-making, as well as different from that which would maximize fulfilment of the patient's conventional health outcome preferences. 'Shared' and 'informed' are therefore best interpreted as attributes of the relationship model, with future research focusing on the more relevant, higher level, goal of *better* decision-making. This is a concept which will have to embrace both meta- and health state preferences and patients will be genuinely empowered only when they make any needed trade-off between fulfilment of their meta-preferences and their health state preferences on an informed and transparent basis.

Evaluating decision aids and decision technologies

The purpose of CODA, the Clinical Guidance Program¹ (CGP) is to provide, in real clinical time, the quantitative results of modelling a management decision, using the best available evidence- or more realistically a highly defensible body of evidence – in conjunction with the patient's preferences over health outcome states elicited *in situ*. The program is best thought of as providing a decision analysis-based 'third opinion' rather than as a decision aid or support as conventionally conceived (see below). It is accordingly very different from previous systems such as decision board⁷⁻⁹ the probability or treatment trade-off method¹⁰⁻¹² and various 'interactive' video programmes.¹³⁻¹⁵ Generalising about these, Holmes-Rovner writes

Decision supports go beyond traditional informed-consent approaches, to engage the patient in grappling with the elements of the decision, as well as understanding the alternatives. ... Some incorporate values or utilities, in a heuristic, but not prescriptive fashion. Most have decision analysis behind them to organize the presentation of the outcome data, but do not explicitly reveal the rational intent of the analysis. They deliberately leave out the 'right' answer.¹⁶

However, the fundamental aim of CODA and other CGPs is to make transparent the 'rational' intent of the analysis and to offer the answer produced by that analysis. However, this

'answer' is properly characterized as a defensible candidate for 'best' answer, rather than for 'right' answer, because the latter will rarely if ever exist. And it is only a candidate for best answer, given the assumptions, data and structural/institutional constraints built into its use. However, this qualification is true of *all* modes of decision-making, including any that will be used instead of the CGP or to reject its guidance.

One vital consequence is that we are primarily concerned with the quality of its guidance and not whether that guidance is accepted and/or implemented. There are multiple reasons why guidance of the highest quality might be rejected (Dostoevsky's *Notes from Underground* is a more readable source than most psychological texts) and CODA makes no attempt to persuade the patient (or doctor) to follow the guidance, other than noting that the result follows from a serious analysis of the decision using the patient's preferences over outcome states. The third O'Connor criterion for the evaluation of a decision aid¹⁷ – that it is 'effective' (i.e. implemented) – is accordingly seen as inappropriate, in that it assumes either that patients are 'rational' or that it is the function of the aid to make them more so.

As a practical way of implementing decision analysis in the clinical encounter the CGP is put forward rather as a *mode of decision-making* – a way of arriving at clinical decisions or recommendations – not something which is seen as making a contribution to, or within, some other mode of decision-making. The main alternative, and currently dominant, modes of decision-making are 'traditional clinical judgement' on the one hand and 'evidence-based clinical expertise' (increasingly facilitated through evidence-based guideline statements or algorithms) on the other.¹⁸ (Decision-making by following a 'knowledge-based expert system' represents a third but largely hypothetical possibility.)

How, then, should an intervention such as a CGP be evaluated? Is it really an 'intervention' at all? Most researchers designing evaluation instruments^{19,20} assume that decision aids should be designed to help the patient make an

informed choice in a decision-making process where the mode of decision-making used by the clinician is a given and usually assumed to be 'traditional clinical judgment'. Most current research and commentary on decision aids and support systems also assumes that the key patient preferences that need eliciting (or constructing) are those impinging on choices regarding the medical management of their condition, typically phrased as the patient's preferences in relation to the knowledge and information necessary to adequately comprehend 'the risks' and 'the benefits' of the various options.

The new modes of decision-making ('decision technologies') now becoming available and sure to multiply rapidly in the coming decades, call both these assumptions into question and necessitate serious re-thinking of the methodology of evaluation. Two key issues warrant attention.

One concerns the distinction between *knowledge validity* and *decision validity* in relation to the inputs into any decision-making process. This distinction is developed elsewhere in the context of the 'condition-specific measure' vs. 'generic measure' debate in Health-Related Quality of Life²¹ and cannot be considered further here. The most important implication for the current paper is that the application of knowledge validity criteria in advance of decision validity criteria is a frequent accompaniment of partial or noncomparative evaluation.^{22,23} In this deviation from sound practice the flaws or limitations of a particular method or approach (e.g. decision analysis), established in isolation, are regarded as conclusive without any or adequate consideration of the equivalent flaws or limitations of the alternatives (e.g. clinical judgment).

The issue on which we concentrate here concerns the way the clinical consultation is analysed and modelled. Previous analysts have constructed insightful taxonomies^{6,24} but all have been implicitly or explicitly seeking a *uni*-dimensional classification. The emergence of CGPs, and to a lesser extent expert- and/or evidence-based clinical guidelines, makes it clear

that *two* dimensions are needed. They derive from what can be conceptualized as the two meta-decisions that are made before a clinical encounter proceeds. By definition, these involve *deciding how to decide*. Meta-decision 1 determines which model of the physician-patient relationship is to apply at the outset of the consultation (and, as default, throughout it). Meta-decision 2 determines which modes of judgment and decision-making are to be adopted within the selected model of the consultation. Currently both are made implicitly and (generally) with no explicit discussion or patient consultation. As soon as their existence is recognized it becomes apparent that patients *will* have different 'meta-preferences' in relation to each and should be able to make informed choices on the basis of these two sets of meta-preferences. In the following section we propose a model/mode matrix as a framework within which patients could specify the cells, or cell clusters, within which they wish to locate the upcoming consultation. Clinicians would be entitled to (explicitly) opt out of offering consultation located in particular cells, but increasingly be expected to be competent to perform in multiple roles and modes.

The evidence for the existence of strong meta-preferences of the first type has been around for a long time²⁵⁻²⁷ and recent writings confirm it in a variety of clinical contexts. Two examples will suffice.

Interviewees were divided in their preferences for nondirective counselling: 46% would have liked to get direct advice from the counsellor, 36% said the counsellor should only provide information and not advise the couple about the right decision, and the remainder had mixed feelings. ...Genetic counselling is one of the first medical areas to adopt a nondirective, patient participation approach as its norm – an approach that conflicts with client's prior experience with a directive, paternalistic medical environment. Counselees were equally divided between those who approved and disapproved of this counselling strategy²⁸.

[Our] findings are consistent with other research indicating that younger, more educated patients generally prefer a more active and participatory role in medical consultations and decision-making

than do older and less educated patients. However, patients' perceptions of involvement and control over decision-making did not differ for patients differing in age and education. ...Some people (termed 'blunters') generally avoid information related to their condition while others (referred to as 'monitors') actively seek out this information. ...Future studies ...should assess patient' preferences for their own and their physicians involvement to see if these beliefs explain why some patients are more active communicators than are others.²⁹

In view of the consistency of this finding what is surprising is that many studies still seem frustrated by their failure to establish solid generalizations about patients (or aids). They treat the heterogeneity of patients' preferences as confounders rather than as a fundamental starting point for useful work. A number of reviews and overviews have implicitly accepted this framing.³⁰⁻³² The resulting frustration disappears if the evidence is interpreted in the light of meta-preferences and in a later paper Entwistle notes that:

...individual patients and clinicians vary in their preferences for different approaches and their ability to adopt particular roles in decision-making. Imposing an approach with which either or both parties are uncomfortable may be inconsistent with the notions of respect for individual choice that many of the approaches aim to support.³³

She notes that most developers of conceptual models of clinical decision involving patients have adopted a particular normative model, usually one in which the patient plays either a collaborative or an autonomous role. But full acceptance of Entwistle's point will require abandoning two of the basic assumptions held by most of those in the patient empowerment field. One, that patients *should* become more involved and participatory, because it is in their interests to do so – either for the instrumental reason that it is better for their health or because they simply ought to be more autonomous and resistant to directive paternalism. (In most cases for both reasons.). Two, that becoming more *informed* is a necessary condition of being more *involved*.

Interventions to support decision-making can be seen as affecting a wide range of processes and outcomes, such as:

...knowledge and understanding; who contributes in what way to decision-making; what factors influence the choice made; the lengths of (and hence the costs and numbers of other available) consultations; the quality of the decision made; professional-patient relationships (in both the short and longer term); the delivery of health-care; health-related behaviours; the outcomes of health-care; people's general sense of wellbeing; and their expectations and satisfaction of patients, their families and health professionals with various aspects of health-care and its outcomes. People will have different opinions about which of these criteria are most important and how they value particular effects.³³

But the vital methodological issue is *whose* preferences are to be accorded priority in respect of any and all of such aspects. If it is accepted that it is the individual patient's preferences that count then the idea that aids and supports can be evaluated in anything but *preference-based trials*, where the preferences relate to aspects of the decision-making process and not to management options, is ruled out.

The first assumption (that patients should become more involved) is typically left latent rather than made manifest, so the fact that it clashes with the view, typically quite explicit in the same writing, that patient's preferences should be respected, is rarely noticed, let alone highlighted. But the conflict is clear and once it is exposed one needs to take a position on it. Our personal position is that patient's *current* meta-preferences should be respected in the upcoming clinical consultation, and that it is the task of education, as in all other areas of personal life, to 'develop' these preferences and ensure that they are based on adequate knowledge and exploration of the consequences of holding different ones. The clinical consultation is not the place for this personal preference development in relation to health-care decision-making and it should not be seen as exclusively or even primarily the responsibility of doctors.

The second assumption (that becoming more informed is a necessary condition of becoming

more involved) seems so obviously true that it is never questioned. However, as we will see when we set up the model/mode matrix, the most 'rational' and involved of all patients may be one who seeks intense value clarification and substantial decision responsibility – but wants little or no 'information'.

The model-mode matrix for clinical decision-making

The patient is assumed to have preferences regarding the way judgements and decisions are made about their medical care as well as preferences regarding the health states that are the foci of those judgements and decisions. Specifically, they have a preferred model of the doctor–patient relationship and, conceptually independent though probably empirically correlated, a preferred mode of judgement and decision-making within that preferred type of relationship. These two meta-preferences are relevant to the two meta-decisions taken before a consultation begins. At the moment these are taken implicitly, but we can envisage them increasingly being taken explicitly as the range of decision technologies expands and patients (and doctors) come to know of their availability through the internet and personal networks.

These meta-preferences relate to the individual consultation. They may vary from case to case, not only as the presenting condition of the patient changes, but also as the sequence of consultations within an episode progress. The degree to which the initially agreed character of a consultation can be changed during it would be up to the parties, but the existence of flexibility in this respect in no way undermines the value of the framework in locating and illuminating what is going on at any point. Neither does the 'instability' of an individual's meta-preferences through time. Such lability of preferences is well-known to make analytical decision-making more difficult but its existence is not a ground for ignoring or denying it.

It might seem that these meta-preferences relate exclusively to what Elwyn and co-workers call 'the second half of the consulta-

tion'.³⁴ They are referring to general practice, where the early rituals of the consultation can certainly take up a high proportion of the available time. But even here we suggest that a clearer identification of all management decision-making (including decisions about diagnostic strategies as well as therapy) will bring a very high fraction of the encounter within the scope of the framework.

At this stage the precise specification and wording of the attributes and levels are still under development, as is the instrument to capture patient's meta-preferences. However, this is the appropriate time to air the broad issue. It may or may not be necessary to point out that any suggestion that the framework is too simple needs to be made in full realization of the practical consequences of further additions. And that any suggestion that it is too complex involves denying the importance of distinguishing between the identified elements.

The multidimensional model of the relationship

What the patient wants from the doctor

The patient's relationship with the doctor is defined in terms of the three functions which the patient wants the doctor to undertake (or not, as the case may be). Each function has 3 levels. These are numbered 2, 1, and 0, but no weighting or other normative significance is implied by their use.

Decision responsibility

2. Make the decision
 1. Provide specific (directive) guidance or recommendation
 0. Offer generalized or nondirective advice

Information provision

2. Full decision structure and numerical probabilities
 1. Simplified decision structure, selected probabilities (a few numerical, most verbal)
 0. General verbal description of options, main possible outcomes and chances

Value clarification

2. Full (quantitative) utility elicitation
1. Selected questioning (qualitative); possible quantitative testing of a key trade-off
0. Generalized conversation (or none)

Explicitly outside the model are things which it is assumed all patients will expect to receive (and all doctors expect to deliver), such as:

- emotional support appropriate from a caring professional;
- courtesy, confidentiality and efficient administration of the management process, and
- responsible implementation/performance (often as the licensed 'doer') of any decision taken, e.g. prescription preparation, surgery.

Also excluded is an aspect in which patients will vary, but does not warrant separate attention:

- provision of requested basic knowledge of a purely biological or technical sort. (Insofar as such information is decision-relevant it is covered in the Information attribute.)

While there is nothing radically new in this framework, it does differ significantly from all previous suggestions in numerous ways. For example, in relation to the pioneering Autonomy Preference Index of Ende and co-workers³⁵ with its decision-making and information seeking components, we distinguish clearly between 'decision' and 'recommendation' in relation to the former, confine 'information' to that which is decision-relevant and give the term specific content, and, finally, add the now accepted as essential value clarification component.

The modes of judgement and decision-making

How the patient wants the doctor to arrive at what he or she provides

The patient has preferred modes of judgement and decision-making. These define how they wish the above functions to be fulfilled by the doctor, in other words the mode they would like

to be treated as primary in each case and given dominant weight or emphasis. The modes are defined in terms of the Analysis-to-Intuition Ratio of Hammond's Cognitive Continuum.³⁶⁻³⁸ where increases in the A-I ratio involve increases in the precision with which concepts are defined, relationships are specified and magnitudes are measured. Higher A-I ratios generally reflect and require increasing control over the task. Note that increased precision will often take the form of being more 'precisely inexact'.

The six broad modes imposed on the continuum (Fig. 1) are *exemplified* – not defined – as follows:

6. personal experience-based clinical judgement
5. evidence-based consensual expertise and guidelines
4. decision analytic modelling
3. the observational/epidemiological study
2. the randomized controlled trial
1. the scientific experiment

The numbering of the modes has no intrinsic normative significance other than providing an ordinal indication of the A-I ratio. Modes 1–3 are essentially research ones, so mode 4 is actually the highest A-I ratio in the present, *practice decision-making*, context.

The model-mode matrix

Crossing model with mode creates an initial matrix of 27 cells and forms a framework within which we can explore the issues surrounding the evaluation of the clinical consultation in general and the contribution of decision aids and support systems in particular.

In fact, the 27 cells quickly reduce to 18, as Table 1 shows.

Three cells, labelled x-ia, disappear when it is recognized that higher information provision preferences cannot be fulfilled by insufficiently analytical modes. And another 6 are lost when the patient's desired level of involvement in value clarification rules out 3 as insufficiently analytical and 3 as over-analytical (x-oa).

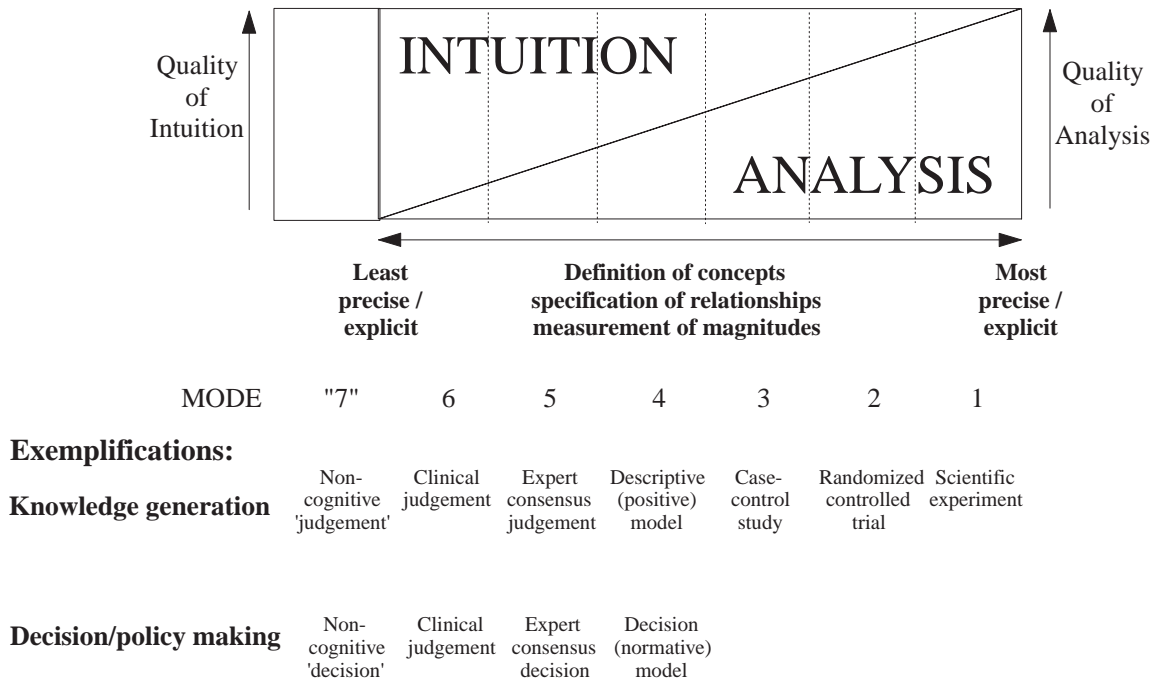


Figure 1 The cognitive dimension of the Cognitive Continuum framework.

| Relationship model | | Judgement and decision mode (reflecting Analysis-Intuition ratio) | | |
|-------------------------|---|--|--------------|------------|
| | | 6 Low A-I | 5 Medium A-I | 4 High A-I |
| Decision responsibility | 2 | | | |
| | 1 | | | |
| | 0 | | | |
| Information provision | 2 | (x-ia) | (x-ia) | |
| | 1 | (x-ia) | | |
| | 0 | | | |
| Value clarification | 2 | (x-ia) | (x-ia) | |
| | 1 | (x-ia) | | (x-oa) |
| | 0 | | (x-oa) | (x-oa) |

Table 1 The model-mode matrix

Of course many cell preferences (most of those where the Mode is 4 or 5) could not be accommodated at the moment, even if requested by patients from doctors willing in principle to offer such modes. It is important to remember that our intention here is to ensure that evaluation of the new technologies capable of fulfilling these preferences are properly evaluated as and when they do arrive.

There are many more than 18 possible individual sets of preferences in the framework

because each of the nine valid Decision responsibility (DR) cells may, at least in principle, be coupled with any of the six valid Information provision (IP) ones and with any of the three valid Value clarification (VC) ones. The total number of permutations is therefore 162. No particular point is served at the moment by presenting a full tabulation. A few selected examples should enable the reader to assess the value of the framework for determining the suitability or unsuitability of particular aids or

supports and ensuring that their evaluation is conducted properly.

The patient meta-preference codes come in the form of a pair of numbers for each dimension. Within each pair the first number represents the preference level within the dimension concerned, the second the Mode preference for that dimension.

Example 1: DR2/6-IP0/6-VC0/6

This is the patient who says ‘do what is best for me doctor’, wants the doctor to take the decision without bothering them with information or value clarification and prefers the doctor to base his or her decision on their traditional clinical judgement. The importance of distinguishing model from mode is confirmed when we point out that DR2/5 – IP0/6 – VC0/6 and DR2/4 – IP0/6 – VC0/6 are identical to our example in terms of their relationship desires, but wish the doctor to take his decision on their behalf by a more analytical approach, for example by a Clinical Guidance Program in the case of DR2/4 – IP0/6 – VC0/6. (They would have to use default population values in the analysis, given that this patient does not want any personal value clarification.)

Example 2: DR0/6 – IP1/5 – VC1/5

The patient who says ‘I want to take the decision myself without even a recommendation, but I would like a fair bit of decision-relevant information and some help in clarifying my values’. The treatment trade-off approach and the O’Connor weigh scale aid^{39–41} would seem to be ideally suited to this patient. The standard decision board is more appropriate for DR0/6 – IP1/5 – VC0/6 who prefers to opt out of any value clarification.

Example 3: DR1/4 – IP0/6 – VC2/4

The patient who says ‘What I want is a specific recommendation, based on a decision analysis of the choice facing me which draws on full elicitation of my preferences and combines them with the best available evidence. I don’t want to

be burdened with any of the latter.’ The CGP is ideal for this patient. The ‘decision analysis information model’ of Holmes-Rovner and co-workers⁴² would not be suitable in this case, but could be for DR1/4 – IP1/5 – VC1/5, who does want some information. However, in taking over 4 h their intervention is accepted to be unrealistic clinically. We see it as undertaking some of the wider educational task that is essential, but regard as most appropriately located prior to and outside any clinical encounter of immediate significance to the patient. Patient education needs to be clearly differentiated from patient decision support and undertaken from a patient-not medico-centred perspective.⁴³

Example 4: DR1/5 – IP1/5 – VC1/5

The patient who constitutes the implicit normative ideal for many authors in the ‘shared and informed’ literature.

Seeing things through this framework makes it clear that the patient’s preferred model/mode combination will predetermine the answers to many of the issues currently under discussion within the decision aid literature, for example, how the patient’s reactions to the revelation of uncertainty and need for trading-off among outcome dimensions are to be regarded. It also makes clear that any *unidimensional* classification system of ‘consultation types and styles’, (e.g. paternalist/shared/informed) cannot reflect the *minimal* complexity of patients’ meta-preferences. As a result it should significantly affect how evaluation of decision support instruments and programmes is conceived and conducted. In brief, the *methodology of evaluation needs to be cell-specific* and the search for generalizations about the effectiveness of aids for ‘patients’ (as a single category) abandoned as likely to be misleading and of dubious or no policy significance. The ‘satisfaction’ with an aid or support system reported by patients in studies using this concept will be largely determined by their meta-preferences.

Apart from its impact on evaluation, formal recognition of the existence of these meta-preferences and meta-decisions should also ensure

that patients become able to choose openly and explicitly the extent to which they wish to be decisionally 'empowered' and 'autonomous', helping give a content to those terms which is often missing. What Ende and co-workers stressed in 1989 remains valid.

Each patient's preference is his or her own and depends upon individual factors, modulated by illness. Enthusiasm for interventions designed to enhance patient autonomy should not interfere with the patient's privilege, which is to receive care and support from a knowledgeable physician. The physician-patient relationship should be based not on preordained policies, but rather on an accommodation to each patient's preferences and needs.³⁵

The arrival of new decision technologies simply requires that the patient's privileges be extended to encompass preferences over the analytical-to-intuitive ratio with which knowledgeable physicians undertake the multiple tasks they face in the consultation.

Conclusions

The current movement for patient empowerment largely takes for granted the virtues of 'shared' decision-making and/or 'informed' decision-making. The time has come for the focus to move from all such intermediate and partial goals to the top-level goal of *better* decision-making. Since we take it as axiomatic that any concept of 'better' must have a basis in *preferences* our framework suggests that two fundamental sets of preferences are relevant to 'better decision-making'. One set is made up of the patient's meta-preferences regarding the process of decision-making, i.e. preferred relationship model and preferred judgement and decision modes. A decision will be better to the extent that it reflects these meta-preferences. The second is the patient's preferences over the health state outcomes that are involved in the decision. Here, a decision will be better to the extent that, given these preferences, it reflects the best relevant patient-specific evidence. If, as seems likely, there will often be conflict between maximising these

distinct sets of preferences, the ethical answer is (presumably) that the competent patient is the one who must make the necessary trade-off – subject to any constraints flowing from the publicly funded character of the health-care system.

It has only been possible to adhere to simple, three or four way, unidimensional, models of the doctor–patient relationship because only one decision technology has been available until recently – that referred to as 'clinical judgement'. But as new decision technologies, embodying increasing analytical content, become available⁴⁴ the attempt to fit things within these simple frameworks will be increasingly invalid and unproductive. The necessity of disentangling relationship model from judgement and decision mode will become ever more starkly evident. A multiattribute model of the relationship which distinguishes the conceptually independent attributes of decisional responsibility, information provision, and value clarification, seems requisitely complex as well as mapping appropriately on to the alternative modes of judgement and decision-making. The question of precisely which patient preferences are to be respected, and how, is made transparent and unfudgable. And the foundation for a coherent and transparent doctor–patient encounter laid.

If patient preferences are to be taken seriously they must be taken as fundamental in the same way that their clinical condition is taken as fundamental. No one would suggest trialling a drug targeted at a particular disease on a random group of patients, irrespective of their diagnosis. In relation to the design and evaluation of decision aids and modes, meta-preferences regarding relationship model and judgement and decision-making mode should be treated as the equivalent of the clinical condition.

In summary

Any further research on patient involvement in decision-making should be focused on the search for the *best* or *better* decision and address the issues of shared and informed decision-making

within a framework that focuses on this top-level target.

Any concept of better or improved decisions will need to be patient preference-based (as well as evidence-based) and should embrace the meta-preferences of patients over the doctor–patient relationship on the one hand and the modes of judgment and decision-making within that relationship on the other.

The doctor–patient relationship is most usefully conceptualized within a multiattribute model structure with Decision Responsibility, Information Provision, and Value Clarification as the key dimensions.

The judgement and decision modes must be regarded as distinct since the DR–IP–VC dimensions can be fulfilled at very different analytical-to-intuitive ratios.

Crossing the two dimensions establishes a matrix of cells that can be used to locate the heterogeneous population of patients and, since evaluation of decision aids should be cell-specific, help develop appropriate methodologies for this exercise.

In the DR–IP–VC model as proposed each of the 3 dimensions has 3 levels. The precise number of levels and their characterization are less important than the need for some such structure. The matrix should be requisitely complex – as simple as possible given the task for which it is needed and no more. Familiar simple classifications such as the ‘paternal-shared-informed’ models of the doctor–patient relationship are no longer up to the task, though they have stimulated much useful work in the field.

The recognition and respecting of patient meta-preferences will need to be accompanied by a realization that fulfilment of these may not be fully compatible with fulfilment of patient’s health state preferences. (In other words seeking the optimal course of action in relation to the latter may rule out some meta-preference fulfilling cells.) Patients can be regarded as truly empowered only when they are made aware of this possible conflict and make any needed trade-offs on an informed and transparent basis.

Modes of clinical decision-making can be properly evaluated only (a) in relation to each other and (b) without assuming any particular mode is best a priori and hence constitutes the ‘gold standard’. Breach of either rule constitutes partial or noncomparative evaluation.

All evaluation, including cell-specific evaluation of decision aids and modes, should be by the most rigorous interventionist methodology practical, ideally at mode 2 or 3 as with other technologies. Clinicians should not seek, or be allowed, to resist such evaluations on the unacceptable ground that such studies would be ‘unethical’ or unnecessary because clinical judgement can or must be taken as the gold standard decision technology.

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References

- 1 Pell I, Dowie J, Clarke A, Kennedy A, Bhavnani V. Development and preliminary evaluation of a Clinical Guidance Programme for the Prophylactic Oophorectomy Decision. *Quality in Health Care*, 2002; in press.
- 2 Robinson A, Thomson R. The potential use of decision analysis to support shared decision making in the case of uncertainty: the example of atrial fibrillation and warfarin anticoagulation. *Quality in Health Care*, 2000; **9**: 238–244.
- 3 Thomson R, Parkin D, Eccles M, Sudlow M, Robinson A. Decision analysis and guidelines for anticoagulant therapy to prevent stroke in patients with atrial fibrillation. *The Lancet*, 2000; **355**: 956–962.

- 4 Sanders GD, Hagerty CG, Sonnenberg FA, Hlatky MA, Owens DK. Distributed decision support using a web-based interface: prevention of sudden cardiac death. *Medical Decision Making*, 1999; **19**: 157–166.
- 5 Aoki N, Lee A, Nagata S, Obbu S, Fukui T, Beck J. Web and evidence based decision support system (WEDS) combined with clinical patient database for patients with glioma (Abstract). *Medical Decision Making*, 1999; **19**: 530.
- 6 Charles C, Gafni A, Whelan T. Shared decision-making in the medical encounter. what does it mean? (Or it takes at least two to tango). *Social Science and Medicine*, 1997; **44**: 681–692.
- 7 Levine MN, Gafni A, Markham B, MacFarlane D. A bedside decision instrument to elicit a patient's preference concerning adjuvant chemotherapy for breast cancer. *Annals of Internal Medicine*, 1992; **117**: 53–58.
- 8 Whelan T, Levine M, Gafni A, Lukka H, Mohide E *et al.* Breast irradiation postlumpectomy: development and evaluation of a decision instrument. *Journal of Clinical Oncology*, 1995; **13**: 847–853.
- 9 Sebban C, Browman G, Gafni A *et al.* Design and validation of a bedside decision instrument to elicit a patient's preference concerning allogenic bone marrow transplantation in chronic myeloid leukemia. *American Journal of Hematology*, 1995; **48**: 221–227.
- 10 Llewellyn-Thomas HA, McGreal MJ, Thiel EC, Fine S, Erlichman C. Patient's willingness to enter clinical trials: measuring the association with perceived benefit and preference for decision participation. *Social Science and Medicine*, 1991; **32**: 35–42.
- 11 Llewellyn-Thomas HA, Williams JI, Levy L, Naylor C. Using a trade-off technique to assess patients' treatment preferences for benign prostatic hyperplasia. *Medical Decision Making*, 1996; **16**: 262–272.
- 12 Brundage MD, Davidson JR, Mackillop WJ, Feldman-Stewart D, Groome P. Using a treatment-tradeoff method to elicit preferences for the treatment of locally advanced non-small-cell lung cancer. *Medical Decision Making*, 1998; **18**: 256–267.
- 13 Wagner EH, Barrett P, Barry MJ, Barlow W, Fowler FJ. The effect of a Shared Decision Making program on rates of surgery for benign prostatic hyperplasia: pilot results. *Medical Care*, 1995; **33**: 765–770.
- 14 Shepperd S, Coulter A, Farmer A. Using interactive videos in general practice to inform patients about treatment choices: a pilot study. *Family Practice*, 1995; **12**: 443–447.
- 15 Kasper JF, Mulley AG, Wennberg JE. Developing shared decision making programs to improve the quality of care. *Quality Review Bulletin*, 1992; **18**: 183–190.
- 16 Holmes-Rovner M. Evaluation standards for patient decision supports. *Medical Decision Making*, 1995; **15**: 2–3.
- 17 O'Connor AM, Rostom A, Fiset V *et al.* Decision aids for patients facing health treatment or screening decisions: systematic review. *British Medical Journal*, 1999; **319**: 731–734.
- 18 Dowie J. Decision analysis in guideline development and clinical practice: the 'Clinical Guidance Tree'. In: Selbmann HK (ed.) *Guidelines in Health Care*. Baden-Baden: Nomos-Verlagsgesellschaft, 1998: 162–193.
- 19 Holmes-Rovner M, Kroll J, Schmitt N *et al.* Patient satisfaction with health care decisions: the satisfaction with decision scale. *Medical Decision Making*, 1996; **16**: 58–64.
- 20 O'Connor AM. Validation of a decisional conflict scale. *Medical Decision Making*, 1995; **15**: 25–30.
- 21 Dowie J. Decision validity should determine whether a generic or condition-specific HRQOL measure is used in health care decisions. *Health Economics*, 2002; in press.
- 22 Dowie J. The danger of partial evaluation. *Health Care Analysis*, 1995; **3**: 232–234.
- 23 Dowie J. The 'pathology' of decision making in clinical practice and a framework for evaluations. In: Selbmann HK (ed) *Guidelines in Health Care*. Baden-Baden: Nomos-Verlagsgesellschaft, 1998, 27–41.
- 24 Emanuel EJ, Emanuel LL. Four models of the physician-patient relationship. *Journal of the American Medical Association*, 1992; **267**: 2221–2226.
- 25 Benbassat J, Pilpel D, Tidhar M. Patient participation in decision making. *Behavioral Medicine*, 1998; **24**: 81–88.
- 26 Guadagnoli E, Ward P. Patient participation in decision making. *Social Science and Medicine*, 1998; **47**: 329–339.
- 27 Strull WM, Lo B, Charles G. Do patients want to participate in medical decision making? *Journal of the American Medical Association*, 1984; **252**: 2990–2994.
- 28 Shiloh S, Reznik H, Bat-Miriam-Katznelson M, Goldman B. Pre-marital counselling to consanguineous couples: attitudes, beliefs and decisions among counselled, noncounselled and unrelated couples in Israel. *Social Science and Medicine*, 1995; **41**: 1301–1310.
- 29 Street R, Voigt B, Geyer C, Manning T, Swanson G. Increasing patient involvement in choosing treatment for early breast cancer. *Cancer*, 1995; **76**: 2275–2285.
- 30 Coulter A. Partnerships with patients: the pros and cons of shared clinical decision making. *Journal of Health Services Research and Policy*, 1997; **2**: 112–121.
- 31 Entwistle VA, Sowden AJ, Watt IS. Evaluating interventions to promote patient involvement in decision making: by what criteria should effectiveness be judged? *Journal of Health Services Research and Policy*, 1998; **3**: 100–107.
- 32 Molenaar S, Sprangers MA, Postma-Schuit FC, Rutgers EJ, Noorlander J *et al.* Feasibility and effects

- of decision aids. *Medical Decision Making*, 2000; **20**: 112–127.
- 33 Entwistle V. Supporting and resourcing treatment decision making: some policy considerations. *Health Expectations*, 2000; **3**: 77–85.
- 34 Elwyn G, Edwards A, Kinnersley P. Shared decision making in primary care: the neglected second half of the consultation. *British Journal of General Practice*, 1999; **49**: 477–482.
- 35 Ende J, Kazis L, Ash A, Moskowitz MA. Measuring patient's desire for autonomy: decision making and information-seeking preferences among medical patients. *Journal of General Internal Medicine*, 1989; **4**: 23–30.
- 36 Hamm R. Clinical intuition and clinical analysis. expertise and the cognitive continuum. In: Dowie J, Elstein A (eds.) *Professional Judgment: a Reader in Clinical Decision Making*. Cambridge: Cambridge University Press, 1988, 78–105.
- 37 Hammond KR. *Human Judgment and Social Policy. Irreducible Uncertainty, Inevitable Error, Unavoidable Injustice*. New York: Oxford University Press, 1996.
- 38 Dowie J. What decision analysis can offer the clinical decision maker. *Hormone Research*, 1999; **51**: 73–82.
- 39 O'Connor AM, Tugwell P, Wells GA *et al*. A decision aid for women considering hormone therapy after menopause: decision support framework and evaluation. *Patient Education and Counseling*, 1998; **33**: 267–279.
- 40 O'Connor AM, Tugwell P, Wells GA *et al*. Randomized trial of a portable, self-administered decision aid for postmenopausal women considering long-term preventive hormone therapy. *Medical Decision Making*, 1998; **18**: 295–303.
- 41 O'Connor AM, Wells GA, Tugwell P, Laupacis A, Elmslie T, Drake E. The effects of an 'explicit' values clarification exercise in a woman's decision aid regarding postmenopausal hormone therapy. *Health Expectations*, 1998; **2**: 21–32.
- 42 Holmes-Rovner M, Kroll J, Rovner DR, Schmitt N, Rothert M *et al*. Patient decision support intervention: increased consistency with decision analytic models. *Medical Care*, 1999; **37**: 270–284.
- 43 Skelton AM. Patient education for the millennium: beyond control and emancipation? *Patient Education and Counseling*, 1997; **31**: 151–158.
- 44 Eckman MH. Patient-centred decision making: a view of the past and a look toward the future. *Medical Decision Making*, 2001; **21**: 241–247.