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Who should decide how much and what information is important in person-centred health care?



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Abstract

Most guidelines for clinical practice, and especially those for the construction of decision support tools, assume that the individual person (the patient) needs to be in possession of information of particular sorts and amount in order to qualify as having made an ‘informed decision’. This often implicitly segues into the patient having made a ‘good decision’. In person-centred health care, whether, in what form, and with what weight, ‘information’ is included as a criterion of decision quality is a matter for the person involved, to decide in the light of their own values, preferences, and time and resource constraints.

Keywords

decision quality, decision support, informed decision, multi-criteria decision analysis

It seems taken-for-granted by many interested in a patient’s health care decision making, and in providing decision support for it, that only an informed decision can be a good decision, let alone the best possible decision. Being informed is proposed as a necessary, almost sufficient, condition of decisional empowerment, even when there can be no guarantee that the information is translated into understanding. The irony is that this orthodoxy has largely been arrived at without input from those making the decisions.

It is time to question this orthodoxy. Decision quality is a multi-dimensional concept and, therefore, by definition, its assessment is sensitive to the criteria used to determine it and the preference weights attached to them. Currently, decision quality is assessed formally or informally by methods which are dominated by the externally defined and assessed information state of the patient. As a result, he or she is denied the right to decide the attributes of a good decision and assign his or her own personal importance weights to those considerations including how much and what information is important to him/her.

Against the background of the vast literature on normative, prescriptive and descriptive approaches to decision making (Lipshitz and Cohen¹ provide an accessible introduction), we do not have the absurdly broad aim

of defining a good decision. We merely seek to make a narrow point concerning the place currently assigned to ‘being informed’ in assessing the quality of a clinical decision. From the perspective of person-centred health care, the assumption that ‘being informed’ can, and should, be defined external to the individual at the point of decision, needs to be challenged. This includes questioning the closely related assumption that the relative importance to be attached to information criteria in evaluations of clinical decision quality and decision support tools can be defined without reference to the preferences of the individuals in the specific clinical setting.

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Person-centred decision making

Let us take an example from daily life. An individual, as a consumer researcher, wants to buy a refrigerator. With appliances of most sorts, people regard best practice decision making as consulting trustworthy comparison websites and magazines, ones that go beyond expressing opinions, or recording ‘likes’, to numerically rate the alternative products on a set of attributes or criteria. They want these decision support tools to give them ratings that can be trusted because they are produced free of any conflict of interest or other biases. We will refer to them as the BEANs – Best Estimates Available Now. The consumer does not know, and does not want to know, why this refrigerator is given a 4*/80% rating on ‘reliability’, and a 3*/60% rating on ‘environmental impact’, and another one the opposite ratings. Feeling justified in assuming a common sense, lay understanding of the terms ‘reliability’ and ‘environmental impact’, they do not have neither the time nor motivation to find out more about what these concepts mean, in terms of the mechanical functioning of the refrigerator, the quality of its components, the emissions it produces or whatever else contributes to these ratings made by the expert assessors. They do not want to know more about how a refrigerator works.

Some may wish to establish whether consumers have made ‘an informed decision’ by seeing how well they score on a test of refrigerator knowledge. Giving considerable and *fixed* weight to knowledge in their measures of decision quality, consumers’ decisions might be regarded as poor quality, because their knowledge subscore is low.^{2,3} In contrast, consumers may regard themselves as having made good decisions, indeed the best possible decisions they could make, given the time and cognitive effort they are willing to devote to research into the decision-making process including accessing and accumulating knowledge deemed important, even essential, by others.

But surely health care decisions are different from buying refrigerators? Choosing between surgery and medical options for newly-diagnosed cancer, or pain management for chronic osteoarthritis, is not like buying a household appliance, is it? In fact, nothing really changes for the individual, whom we now conceptualize as a researcher conducting a continuing, informal n-of-1 study into his/her health. The affective and emotional differences between the two situations may well produce differences in the decision-making process, but the patient accepts that this will not necessarily enhance the quality of the decision – as he/she defines it. Patients may become interested in finding out more about their medical condition than they would about refrigerators, and actually do so. But unless it leads to a change in a performance

rating for an available option on one of their criteria – especially the ‘BEAN’ for a criterion they weigh heavily – the additional information they now possess is decision-neutral. People-as-researchers may feel better informed in some sense, but they realize they will not necessarily be in a position to make a better decision and therefore have not ended up more *decisionally* empowered. They may even simply have become more anxious and regretful about the opportunity costs of acquiring the information, in the form of the foregone benefits from other activities in which they could have engaged.

Have these patients made an ‘informed’ decision? According to themselves and us, absolutely, since they have consulted a transparent set of option performance ratings on relevant criteria, originating from a source that they have decided is the *most* trustworthy. They have combined these with their criterion importance weights. Their decision quality score may well be low according to an instrument that weights highly the knowledge that they are assumed by others to need to make an ‘informed’ decision. The growing number of condition-specific decision quality instruments being developed, notably by Karen Sepucha and colleagues, all give very heavy weight to a knowledge subcomponent.⁴⁻⁶ There could be no clearer confirmation of the issue at stake here than the title of one of the background papers to these projects: ‘How does feeling informed relate to being informed?’⁷

Trust

Trust is crucial here. In either shared or unshared decision making, trust relates to the inputs into decision making, since we have left behind the notion of an agency relationship, previously dominant in conceptualising medical practice. Trust is always a matter of degree, rather than a binary all or nothing, whether it relates to the BEANs provided by the clinician, or by a decision support tool. Furthermore, it is always the *relative* trustworthiness of the sources that matters. Even if there is only one, dubious, source, it will be the most trustworthy. Unless, that is, the person rates his/her own estimates as more trustworthy than the best source, since – it is easy to forget – these will always be the ultimate assessment. So we envisage an individual regarding the respected consumer magazine’s BEANs on refrigerators as the most trustworthy in relation to that purchase decision. People’s task in health care decisions, given a restricted willingness to devote time and energy to processing information, is to assess the trustworthiness of the available sources of BEANs for the outcomes and other criteria important to them. They would expect a clinician, or a team developing the ratings for a decision aid, to be highly

trustworthy and to be provided with evidence for this, especially in the case of an aid.

The key information the person-as-researcher requires is labelling that ensures he/she will get 'what it says on the tin' when they open an aid. With this meta-information, they can make an informed choice about which tins of what size to open.

The other major problem with any imposed information requirement is that it condemns many on the continuum of health literacy, and especially health numeracy, to receiving little or no help. We fully support attempts to reduce health illiteracy and innumeracy, especially their decision-focused forms. However, it is too much to expect of a decision support tool – or a clinician – to overcome the limitations of previous education and socialization in these respects. Moreover, it is important to accept that even if aid users are able to register and report the relative numbers of sad and smiley faces in frequency diagrams, or repeat back '1 in x' statements – about which there is considerable doubt^{8,9} – this does not in any way ensure that they can meaningfully incorporate the numerical probabilities they have correctly registered (say 10% and .05%, or 1 in 10 and 1 in 2000), into their decisions. This is not to say that a decision aid should not contain help in this respect, including guidance on how the person can best avail themselves of what it offers, and information on the bases of that offering. It is to suggest that much of this should be provided on an opt-in basis.

The wider contexts of person-centred health care

Nothing in what we have said is intended to imply that the community is not entitled to apply community-level criteria and weights to what it provides, or allows to be provided, to whom, under what conditions, and at what cost, in the pursuit of goals such as efficiency, equity and justice. Formal laws and regulations (including those on informed consent and clinician liability) and resource allocation policies (including reimbursement decisions) will be the context in which the individual decision is made, and they will frequently be in conflict with what an individual sees as best for him/herself, given personal criteria and weights. External consequences for others may trump individuals' preferences, as in the case of infectious diseases. But that is life as lived in society.

Trickier are the issues of social responsibility or morality which are not dealt with formally. Apart from issues of environmental and social impact (such as those arising from hormonal treatments and opioids), there are all those that arise in resource-constrained and interdependent systems simply as a result of those constraints and interdependencies. In these cases, we

say two things. First, it is not the function of individual decision support tools to mandate the inclusion or exclusion of 'social' criteria in an individual's set, such as concern for others' health, or insist that these be given specific weights. Those are tasks for the bodies politic and cultural, through education and debate. However, the support should permit and facilitate inclusion or exclusion of such 'externalities', to the maximum practical degree possible, as items in a 'Pick Your Own' criteria menu made available to the person-as-researcher. Second, that in order to be regarded as having made a high-quality decision, the individual should not be required to be *informed* about the social criteria they do select, other than having the processed BEANs available to them from a trustworthy source.

Normative checklists for decision support tools, such as those constructed in accordance with the guidelines of the IPDASi collaboration,¹⁰ are clearly intended to promote person-as-patient empowerment. But most decision aids that comply with these guidelines are designed for use only within the context of shared decision making, in which the person is assigned the status of patient. In many cases, the support can be accessed only within the clinical encounter, or with provider permission. They all perpetuate the idea that only a decision informed in a particular way and to a particular extent can be a good decision.

We do not need the concept of an 'informed decision', only that of a good, better or best possible decision. For none of these will there be a definition that is not multi-dimensional and therefore preference-sensitive. The question is to whose preferences should the definition be sensitive? There can only be one answer: the patient's – or the person's if they are not a patient.

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