Studying patients' preferences in health care decision making

Health Services Research Group

Clinicians repeatedly encounter issues associated with helping patients choose between treatment options. In addition, an interest in patients' decision making stems from growing patient consumerism, the debate about the allocation of scarce health care dollars and the ethical imperative to promote patient autonomy through better informed consent. This article accordingly aims at helping clinicians to approach systematically the research on patient decision making.

Dimensions to patients' perspectives

Three aspects of patients' perspectives on health care decisions have been explored: information, expectations and preferences.

Studies of patients' *information* needs have focused on the sources, detail and accuracy of clinical information. Descriptive studies have assessed the information that patients say they want, compared it with what they get and related any discrepancies to measures such as satisfaction with care.[1,2] Experimental studies have developed and evaluated teaching strategies for providing patients with information.[3,4]

Descriptive studies of *expectations* have investigated patients' views of the risks and benefits associated with their health care decisions, assessed the accuracy of these perceptions and examined how patients interpret the words used (e.g., in consent forms) to describe clinical risks.[5,6] Experimental studies have investigated whether patients understand information about risks differently when it is presented in visual or numeric form and whether "framing" probabilities positively or negatively (i.e., emphasizing the benefits or the risks) affects patients' subsequent decisions.[7,8]

Here we concentrate on the empiric investigation of patients' *preferences*, because it has been argued that a person's decisions are ultimately determined by his or her values.[9] Studies of patient preferences vary in approach:[10] economists, cognitive scientists, ethicists and anthropologists have all used disparate research strategies. In current health services research the most popular techniques are derived from economics. We do not necessarily advocate these methods over others, but they merit particular attention because they are becoming so widespread.

What is a "preference"?

"Preference" refers to the level of satisfaction or desirability that a person associates with a particular health state (e.g., chronic angina), treatment process (e.g., hemodialysis), duration of treatment or illness, or level of participation. A key (and arguable) assumption is that a preference is an entity in a person's mind that we can measure by specific methods;[11] thus we can satisfactorily determine a patient's strength of preference for the health-related variable under study.

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Preferences for health states

Studies of preferences began with attempts to assign scores to patients' judgements about the desirability (or undesirability) of different health states.[12-14] Such judgements remain helpful in comparing the severity of various states or in assessing treatments. Preference-based scores are a useful complement or an alternative to symptom indices or pencil-and-paper questionnaires that sum different items for an overall "quality-of-life" score. In analyses of clinical decisions and cost-effectiveness these overall scores are often incorporated into models to indicate the relative desirability of health states after treatment.[15,16]

Depending on the purpose of the research, an investigator may be interested in illnesses that a patient is experiencing or expects to experience or in conditions that a healthy person imagines others to be experiencing. If the research purpose and the selection of raters do not match, inappropriate generalizations may be made.[17]

Another design issue is how to go about describing a particular health state. Health care providers and patients may hold different views about which attributes of a health state are crucial, and unexpected connotations may be associated with particular words and phrases.[18] Even the presentation format used — written in narrative or point form or shown on videocassette — can make a difference to the respondent's subsequent preference score.[19]

A second contentious issue is how to go about getting a preference score from respondents after the health state has been described to them. There are three common approaches.

The "standard gamble" was originally developed to assess attitudes about different states of wealth.[20] In health care applications the respondent is asked to consider a hypothetic choice involving a health state. For example, the options may be to continue living with continued hemodialysis or to take a gamble. The gamble has two possible outcomes: the "best" is usually the immediate restoration of perfect health (arbitrarily assigned a value of 1), and the "worst" is immediate death (assigned a value of 0). The first version of the gamble is set with a very high probability of the rater achieving the best outcome; the rater then tends to choose to gamble, and the task proceeds. This probability is progressively reduced until the respondent cannot choose between continued life in the described health state and the gamble. The probabilities at this point and the fixed values for the outcome states are then used to calculate a "utility" score for life with hemodialysis. A utility score measures the strength of a preference in a situation that involves risk.[21] Utility assessment techniques assume, perhaps with undue optimism, that people act rationally under conditions of uncertainty.

A second popular method is the "time trade-off."[22] The procedure begins with an obvious, hypothetic choice between a fixed, long period in a poor health state (e.g., 20 years of dialysis followed by death) and the same length of time in perfect health (also followed by death). After the rater chooses 20 years in perfect health the number of years available in that option is systematically reduced until the respondent can no longer choose between the options. If this happens when the choice is between 15 years in perfect health and 20 years of dialysis, 0.75 (15/20) represents the time trade-off score for the poor health state.

A third approach involves the use of rating scales.[23] The graphic or linear analogue scale, for example, is a line 10 cm long anchored at each end by descriptions of extreme health states (e.g., perfect health, with a value of 100, and death, with a value of 0.) A rater receives a description of a health state and indicates a judgement of its relative desirability by placing a mark on the scale. The preference score for the described state is the distance from 0.

Preferences for treatments

How do we compare patients' views of two treatments that are likely to produce the same results but with different side effects? In the time trade-off method we have seen how times in different health states are varied until the rater has difficulty in choosing one. In the probability trade-off technique[24] a rater's evaluation of one treatment is determined by a comparison with another, given different likely outcomes; the probabilities of the outcomes are varied until the respondent has difficulty in choosing one.

For example, suppose we wish to compare preferences for a new adjuvant chemotherapy protocol with those for standard care (postsurgical follow-up only). The researcher starts by asking the patient to indicate which clinical alternative is preferred. If the patient chooses the new protocol the researcher then either reduces the probability of its benefit (e.g., the chance of 5-year survival) or increases the probability of the same benefit associated with the standard care until the respondent switches his or her stated preference. The usual approach is to vary the chances of benefits rather than of side effects.[25,26] Patients are told that these alterations in the decision problem have nothing to do with their actual situation but are a device for determining how strongly they feel about alternative treatments. Patients could also be asked whether their preferences arise primarily because of attraction to a positive aspect of the preferred alternative or because of aversion to a negative aspect of the rejected alternative. This qualitative information can help researchers — and ultimately clinicians and patients — understand how to improve the treatments.

Preferences for time periods

Patients making health care decisions often have to consider the relative importance of different time periods. These include the time invested now (e.g., in an exercise program) for a possible future benefit (perhaps longer life expectancy), the time involved in waiting for, undergoing and recovering from treatment, and the time spent receiving palliative care. The techniques outlined can be adapted to investigate patients' preferences about different periods in each of these clinical situations. For example, would a patient be willing to invest X years in taking an antihypertensive medication to obtain a reduction of Y in the absolute risk of myocardial infarction? Such an assessment could be an important aspect of the process of obtaining informed consent for lifelong drug therapy. Or, suppose we were interested in finding out how strongly patients would prefer a shorter time on a waiting list for coronary artery bypass surgery. A version of the time trade-off technique has been constructed that meets this objective.[27]

Researchers can also assess patients' views of different times in different states of health.[28] In fact, when a very undesirable health state is being considered, a gamble with a possible payoff of more time in that state becomes perceived as punitive. Thus, respondents may choose the gamble, hoping to win immediate death![29] Such studies clearly have implications for the design of advance directives.

Preferences for decision-making roles

There are a few approaches to determining attitudes toward participation in decision making about treatment. The questionnaire of Strull, Lo and Charles[30] comprises five statements about responsibility that range from the physician's assuming primary responsibility for decision making to the patient's doing so. Degner and Russell's approach[31] involves presenting patients with picture cards depicting different levels of patient control over treatment decisions relative to control by either their physicians or their families. Patients are asked to rank the cards according to their preferred degree of control. These techniques could explore various questions: Do patients tend to report the same role preferences all the time or do their preferences shift depending on what is at stake? To what extent is the decision-making role experienced by patients consistent with the role that they say they want? If it is inconsistent with their stated preferences does this reduce compliance or satisfaction with care?

Putting it all together

So far, we have been describing quantitative methods that look at preferences about disparate parts of decision making. The healthy year equivalent is a measure that has been proposed to integrate patients' attitudes about several health states in succession, experienced over different periods and interspersed with different treatments.[32] For example, if a particular profile of ill-health covered 20 years one could determine the duration of a profile of good health that the respondent would consider equivalent. Exponents believe that responses to such profiles are more realistic, since patients' health care experiences change over time.

Issues in preference studies

Determinants of reported preferences

Work in oncology and cardiology suggests that stronger preferences for participation in treatment decisions are found in patients who are female, young and highly educated.[30,31,33,34] Very little work has been carried out to assess the influences of cultural and demographic characteristics on preferences, although Canada's multiethnic nature makes this an important issue.

Some effort has been made to find out whether the values obtained from raters are related to actual health status. For example, a healthy person could be asked to imagine and evaluate life with severe osteoarthritis, and then a rating could be obtained from a patient who has that condition. So far, such exercises have yielded intriguing but contradictory results.[35,36]

These disparities have implications for investigators who are trying to obtain mean values for a set of health states, for example, to incorporate those values into decision trees. If preferences vary widely with demographic and disease characteristics, perhaps the sampling of raters must be deliberately stratified and separate analyses carried out for different groups.

Reliability and validity of preference scores

A method of measurement is reliable if it elicits consistent results within the same interview (internal consistency) or on separate occasions (test-retest reliability). Fortunately there is accumulating evidence that the three methods of assessing preferences for health states yield acceptable internal[37,38] and test-retest[39,40] reliability coefficients and that the probability trade-off task generates consistent treatment preference scores[41,42] (depending on how the information is framed).

However, there is no agreement on how to validate the various methods. A diagnostic test result may be compared with biopsy results or autopsy evidence of the disease of interest. "Softer" measures (e.g., quality-of-life questionnaires) can be correlated with other measures (e.g., symptom indices, physiologic measures of disease severity and clinical judgements).[43-45] However, since patient preference scores are subjective it may not matter that two people with equally severe angina pectoris (according to standard clinical and noninvasive indicators) value symptom relief very differently. Therefore, the validity of preference scores has to be addressed in other ways. One could examine the relation between preferences and decisions or behaviour; for example, if a treatment trade-off reveals that a patient strongly prefers treatment A, does he or she actually consent to that treatment rather than an alternative? One could also examine the methodologic robustness of scores: within any given method do scores vary widely depending on the wording used, and how much variation is there between methods?

There has been little systematic work investigating whether preferences correlate with current or future actions. One study indicated that most patients' agreement or refusal to enter a clinical trial was consistent with their reported treatment preferences.[25] O'Connor and associates[46] found that cancer patients' pretreatment preferences did not shift with subsequent experience of therapy. However, this entire area needs further investigation.

Methodologic consistency is also uncertain. For example, when used to assess a patient's attitudes toward a *set* of health states the standard gamble and the rating scale may generate internally inconsistent results.[47,48] The true extent of intermethod agreement is confused by the failure of studies of health state preferences to control for the possible effects of method order,[19] to have large enough samples[37] or to involve patients (rather than physicians).[11]

With regard to treatment preferences, the probability trade-off technique involves presenting risk–benefit information about a set of choices. Results from psychology experiments suggest that preferences are influenced by whether information is framed positively or negatively.[49-51] Similar observations have been made in simulated health situations involving treatment choices,[7,8,52,53] although the influence may not be evident in real decisions involving midrange rather than extreme probabilities.[54,55]

In sum, alterations in presenting judgement problems and eliciting responses can substantially affect how patients report their preferences. This sensitivity has important implications for the very concept of a "preference." Indeed, traditional economic theory assumes that people's decisions rest on preference structures that are well defined, consistent and quantifiable.[56,57] Yet, patients imagining or experiencing unfamiliar states may not offer coherent opinions.[58] Thus, the validity of the score generated by any method under such circumstances is untestable, and the numbers themselves "are hardly compatible with the sort of rigourous systematic thinking" required by formal decision or cost–utility analysis.[59]

In health index construction, in the evaluation of the outcomes of clinical trials and in clinical decision analysis for groups of patients the use of average preference scores runs the danger of "the tyranny of the majority":[60,61] it essentially disregards the opinions of those whose scores are removed from the mean. This ethical problem threatens particularly the validity of cost–utility analysis as the cornerstone of resource allocation decisions.[62]

Rather than focusing on measurement and getting a number that might be meaningless, the assessment procedures described in this article could be used to help physicians and patients share decision making: the patient creates and enunciates his or her own preference structure, the physician understands the patient's emerging preferences, and both parties arrive at a decision that is consistent with this value system.[9] Systematic, controlled studies must be carried out to determine whether these methods do help the patient and the physician in these ways, so that the methods could subsequently be used in various applications. For example, if the treatment trade-off helps patients to understand their choices more clearly, the method may be incorporated into guidelines for patient care.

Conclusion

The changing dynamics of modern health care combined with ethical considerations have lent impetus to studies that attempt to explain the foundations of patient decision making. Research into patients' knowledge, beliefs and preferences will continue. In particular, preference-based approaches are popular research tools for determining the values that patients place on different states of health and for rigorously assessing their views of competing treatment strategies. However, there are many unresolved issues about the methods used to generate scores that purport to summarize a given patient's preferences; the creation of an average profile from aggregate scores is even more problematic. The most valuable outputs of this line of research may be the insights it provides into decision processes and the framework it offers for an explicit information-based approach to shared decision making by clinicians and patients.

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