Review ■

Improving Health Care by Understanding Patient Preferences:

The Role of Computer Technology

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Abstract If nurses, physicians, and health care planners knew more about patients' health-related preferences, care would most likely be cheaper, more effective, and closer to the individuals' desires. In order for patient preferences to be effectively used in the delivery of health care, it is important that patients be able to formulate and express preferences, that these judgments be made known to the clinician at the time of care, and that these statements meaningfully inform care activities. Decision theory and health informatics offer promising strategies for eliciting subjective values and making them accessible in a clinical encounter in a manner that drives health choices. Computer-based elicitation and reporting tools are proving acceptable to patients and clinicians alike. It is time for the informatics community to turn their attention toward building computer-based applications that support clinicians in the complex cognitive process of integrating patient preferences with scientific knowledge, clinical practice guidelines, and the realities of contemporary health care.

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If nurses, physicians, and health care planners knew more about patients' health-related preferences, care would most likely be cheaper, more effective, and closer to the individuals' desires. Along with clinical guidelines, patient preferences provide direction for selecting treatment options and tailoring interventions. Patient preferences also help inform choice in clinical decisions where science has yet to provide dominant solutions to health care problems. Yet eliciting preferences and integrating them into the clinical care process represents a daunting challenge. Decision theory and health informatics offer promising strategies to help meet these challenges.

This paper first reviews the various ways preferences are treated in the health care literature and provides a justification for the health informatics community's attention to patient preferences. It next provides illustrative examples of computer systems that facilitate the elicitation of patient preferences in health care. Finally, it presents to the health informatics community an agenda for attending to patient preferences.

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Background

Preferences

Patient preferences result from deliberation about specific elements, such as anticipated treatments or health outcomes. Patient preferences refer to the individual's evaluation of dimensions of health outcomes and are but one of a large number of preferences that may influence health care choices. These judgments are expressed as statements or actions. Patient preferences result from cognition, experience, and reflection and exist as the relatively enduring consequences of values.[1] It is useful to review the historic antecedents and

contemporary characterizations of the term ''patient preferences.''

Decision Theory: Formalization of Subjective Values

Attention to patient preferences as an input into health care decision-making is rooted in the application of decision theory to the understanding of personal choice. Von Neumann and Morgenstern[2] first proposed that the personal values and attitudes that drive individual choice could be understood through mathematic formulations. Following on their work, Ledley and Lusted[3] introduced the concepts of mathematic reasoning to medical decision-making, with particular attention to decision-making under uncertainty. Raiffa[4] explicated decision analytic strategies that brought the treatment of personal preference and uncertainty into a form accessible in an interpersonal interview. Recently, Pauker et al.[5–7] demonstrated the feasibility of using decision analysis to better understand treatment choices complicated by multiple uncertainties and personal values. These works offer a theoretic foundation for building health informatics tools that aid in the assessment of patient preferences.

The two main branches of decision theory—decision analysis and normative decision theory—both help make patient preferences accessible for clinical decision-making. Decision analysis helps in the choice of one course of action from several when the choice depends, in part, on knowledge of the resolution of the outcomes of that strategy.

Multi-attribute utility theory provided the mechanisms for quantifying the subjective value of health states.[2] It defined preference as the ordering of entities over a value space.[8] The entities about which one developed preferences are discrete objects, such as cars or job candidates, or, in health care parlance, specific health outcomes. Entities were viewed as multidimensional. The value space described the *n*-dimensional intersection of a specific entity described simultaneously on all dimensions. The set of dimensions and their relative weights defined the preference structure. Multi-attribute utility theory provided a way to establish a quantitative expression of an individual's values, with preference for a given health outcome being expressed as a score on the weighted sum of the dimensions and their relative weights.

The work of Pauker et al. provided the operational strategies to move decision analysis into the clinical arena. Pauker's group employed decision analysis to aid patients and clinicians in the challenges of selecting treatment courses when the choice of an intervention depended on two key unknowns: the extent to which a patient preferred the outcomes likely to follow the treatment, and the probabilities that those outcomes would occur. Importantly, they devised the strategies to elicit from patients quantitative estimates of the patient's assessment of the desirability of various outcome states. In a series of studies, this group explored preferences for cancer treatment,[6] prenatal testing,[7] and surgical intervention for cardiac disease.[5] A utility function computed a score for each treatment alternative that explicitly incorporated the probability of each outcome of each treatment and a quantitative estimate of the desirability of the outcomes following each treatment. The treatment with the highest utility value became, by definition, the patient's preference. This use of preference as a synonym for the most desired action is consistent with but not identical to its use in normative decision theory, where an individual's preference for an entity was its utility, a composite of how well that entity performed on each important dimension.

Most informatics tools designed to elicit patient preferences are grounded in these decision theoretic conceptualizations.[9] In this context, the preference statement denotes the extent to which given health states are desirable according to some implicit or explicit valuing scheme. Other uses of the term ''patient preference'' also exist.

Alternative Meanings of the Term "Preferences"

Some use the term ''preference'' to represent an individual's final choice of one option from many possible treatment options. For example, the man coping with an enlarged prostate may be said to have a ''preference for surgery'' if, after considering watchful waiting, medications, and surgical treatment, he decides on surgical intervention as his final choice of treatment.[10] However, this perspective introduces confusion in that the same term is used to refer to the general concept (valuing of a set of treatment) as well as a specific instance (most desired treatment).

Moore and Kramer[11] used the term ''preferences'' to identify those features of cardiac rehabilitation programs deemed most desirable by patients. In this case, the preferences express the desirability to an individual of the features of a program, not the program (entity) itself. Henry and Holzemer[12] identified preferences as ''patient-specific inputs to the care process.'' Under this definition, preferences are atomic judgments that can be integrated with other components of the patient assessment and subsequently used to select treatment strategies.

The phrase ''patient preference'' appears often in the formal health literature, occurring as a concept in more than 5,000 citations and as an explicit keyword

in more than 150 articles indexed in the National Library of Medicine's Medline database. A testimony to the growing importance of preferences in health care is found in the evidence of five times as many citations in the period 1993–97 as in the period 1987–92. The term ''patient preferences'' lacks a consistent definition; many definitions are either implied or explicitly used for the term. Despite these differences in definition, there appears to be convergence in the view that patient preferences are statements made by individuals regarding the relative desirability of a range of health experiences, treatment options, or health states.

Clarifying the exact referent of preferences is a necessary precursor to the design of computer systems to support the use of patient preferences in health care. Donabedian's three-part quality model[13] provides a useful heuristic for sorting out the various referents about which individuals may develop preferences. Individuals may establish preferences about *structural* aspects of health care, such as a preference for belonging to a health maintenance organization[14] or preferences for information or decision-making.[15] Preferences for treatment options, such as surgical rather than medical interventions, represent the individual's appraisal about *process* aspects of health care. A third referent for preference is *outcomes* of health actions.

The distinction between preferences as formalization of an individual's subjective valuing of health outcomes, on the one hand, and preferences as the identified alternative chosen from the set of treatment options, on the other, becomes important when one examines how computers could be of assistance in patient preferences. The exact nature of computer support would vary depending in part on whether one viewed preference as an input to a decision or as the final choice resulting from a decision.

CHALLENGES TO USING PATIENT PREFERENCES IN HEALTH CARE

While the value of understanding and using patient preferences in health care is well recognized,[16] its implementation presents a daunting challenge to clinicians and patients alike.[17] To imagine what a future state of health might be like and to determine the desirability of that future state are complex cognitive tasks. In addition, many patients lack experience in thinking about abstract concepts such as values and preferences. Attempting to do so under the stressful circumstance of the clinical encounter taxes the patient to an even greater degree. Skilled interpersonal interaction can lead to greater understanding of an individuals' preferences.[4–5] The fragmented, time-limited nature of contemporary health encounters leaves little opportunity to conduct the intense, interpersonal exploration needed to elicit and utilize patient preferences. Furthermore, under traditional models of care, patients and clinicians both presumed clinician preeminence in decision-making, and patients frequently prefer to defer to the judgment of the clinician. However, the scientific and clinical knowledge of clinicians does not always provide adequate direction for the treatment of complex illnesses.[17]

Preference assessment is an iterative, cognitive process designed to help a person understand and clarify personal values, health care situations, treatment options, and likely outcomes, and it elicits statements of preference. Benefiting from behavioral decision-making research, an interactive analysis process is used to help an individual focus on key components. Preference assessment can be conducted by a skilled interviewer using probes and reflection. Interactive computer systems can either supplement or supplant the human analyst.

Computer technology can assist in meeting the challenges inherent in employing patient preferences in health care practices. Computer packages that focus on elicitation and values clarification may help patients think hard about complex, abstract issues, such as the desirability of future states.[10] Multimedia displays use sound and full-motion video to help patients envision future states with greater clarity. When delivered via the World Wide Web, these programs facilitate patients' exploration of preferences in the privacy of their homes or away from an anxiety-producing health encounter.[9] In addition, computer technology can store and communicate assessment data gleaned through a human- or computer-directed analysis. Such use of computer technology reduces the demand for repetition on the part of the patient and helps to ensure that data collected once are transmitted in a timely fashion to involved clinicians. Generally, the patient is the direct user in these applications of computer technology.

Reviewed next are five prototypic, experimental systems that aid in the assessment of patient preferences and in communicating those assessments to clinicians.

COMPUTER-BASED PREFERENCE ASSESSMENT

Assessing Utilities of Health States

The Stanford Center for the Study of Patient Preference has pioneered the use of computers and the Internet for low-cost elicitation of patient preferences for health states. Initially, computerized surveys and instructional programs walk the patient through classic

decision analytic methods to help them clarify their preferences. Next, patients approach the rating task through programs that elicit preferences for specific health states.[9,18] These preference assessments use visual analog scales, pair-wise comparisons, and standard gamble methods to measure patient utilities. Through tools developed by the center, data can be collected on a computer with Internet access, Netscape 2.0, and a JAVA script plug-in module. Patient preference data are then checked and stored rapidly and confidentially, ready for analysis.

Cognitive processes involved in the assessment can be quite demanding. For example, the standard gamble and the time trade-off methods deal with abstractions and expression of preferences for life and death and varying degrees of impairment and health conditions. Despite the complexity of the activity, the Stanford Center has shown that computer elicitation of preferences produces valid and reliable results and that this means of preference elicitation is well accepted by the patients. Investigators using the services of the center can download their patients' responses over the Web. In addition to the Internet-based assessments, a stand-alone multimedia preference elicitation software that incorporates health state descriptions (IMPACT) has been tested by the same group. Multimedia descriptions of health states the patients have not yet experienced have been shown to improve understanding of the impact of these states on quality of life and to improve patients' abilities to rate preferences. Multimedia presentations have been used in some studies at the center to describe the effects of antipsychotic drugs and Gaucher's disease.[18]

Choosing Treatment Options

The Comprehensive Health Enhancement Support System (CHESS) is a health promotion and support network application that operates as a module-based computer system for in-home or health care setting use.[19] People with major illnesses or health concerns can access information, decision support, social support, skill training, and a referral resource. Several of the CHESS services help patients clarify their values as they prepare to make decisions that are consistent with their preferences.

Decisions Aid, based on an additive multi-attribute utility model, can be used for condition-specific treatment decisions. The process involves the patient in understanding available options, in choosing possible decision criteria, in assigning weights to the criteria based on preference, and in assigning a utility score to each criterion–option pair. Descriptions of suggested options and criteria or a personal story of someone who chose that option are offered. The program can also accommodate user-preferred options if the expert-generated lists do not contain the desired one. User-weighted decision criteria are shown in bar graph form, displaying the relative importance of all criteria. Likert-type utility scoring of criterion–option pairs are also graphically displayed in conjunction with summaries of how well each option satisfies its paired criterion. The system can also predict the decision the user will make. When used as a conflict analysis aid, CHESS compares the different weights and utilities and identifies areas in which compromise is possible.[20]

Tracking Point Preferences over Time

At Dana-Farber Cancer Institute, reports of health-related quality of life are obtained from cancer patients each time they go to the breast cancer outpatient clinic. Patrick and Erickson[21] define such quality of life as "the value assigned to the duration of life as modified by the social opportunities, perceptions, functional states, and impairments that are influenced by disease, injuries, treatments, or policy." The patient's assignation of a value to her current quality of life, compared with her preference for a health state, can be quantified on a continuum from 0 to 1. The longitudinal elicitation of the patient's perceptions of the effects of both the cancer and the treatment on her quality of life presents the clinician with multiple opportunities to improve patient care. The clinician receives self-reported information that can promote further discussion with the patient about her preferences during the visit. These elicited data also act as feedback to the clinician about the outcomes of care since the last visit. At each point of contact, there is patient-reported information that can provide the basis for customizing patient care plans. In addition, the pen-based application used for the assessment has proved acceptable to patients, minimizes data entry, generates reports, is integrated with the institution's Oracle database, and works on a handheld computer.[22]

Patients' responses to the cancer-specific quality of life instruments (FACT-B and QOL Index) are uploaded by staff from the handheld computer into a desktop system through a wireless limited-range infrared connection. Once the identity of the patient is ascertained, a HyperCard application updates the database with the new responses, which are automatically printed out and attached to the chart for the clinician's viewing prior to the patients' visit.

Envisioning Treatment Alternatives

The technology-based Shared Decision-making Program (SDP) was developed within a framework grounded in the idea that rational treatment decision-

making considers both what the patient wants and what the clinician views as appropriate. The program was designed for use in the clinic setting to aid patients facing complex treatment choices.[23] The SDP for benign prostatic hyperplasia has been clinically tested and evaluated since 1989, and the Foundation for Informed Medical Decision-making has gone on to develop similar programs for other medical conditions, such as low back pain, mild hypertension, breast cancer, and, lately, ischemic heart disease.[24] In the SDP designed for benign prostatic hyperplasia, following diagnosis and introduction to the program, patients receive an information brochure and complete a questionnaire about demographics, current symptoms, feelings about symptoms, and health outcome preferences. Self-reported and other data are entered into the program, which then tailors estimates of risks and benefits to the specific patient situation. In addition to verbal and graphic display of patient-specific probabilities, SDP presents videotaped interviews with persons facing similar problems. For example, in the benign prostatic hyperplasia program, a taped interview with two physician-patients who chose either prostatectomy or watchful waiting is shown so that an understanding of the possible outcomes is made more real. This ''core'' segment lasts 22 minutes. In the ''elective'' segments that follow, the patient may view additional offerings on acute retention, sexual dysfunction, incontinence, and emerging treatments. The elective segments add 25 minutes of material. Printed summaries for the patient and clinician are made available.[10]

A prospective randomized trial to evaluate the impact of the SDP for benign prostatic hyperplasia on subsequent treatment decisions was recently carried out in the state of Washington. After a one-year follow-up, SDP subjects had significantly better scores than control subjects on knowledge of the condition, satisfaction with the process of decision-making, general health perceptions, and physical functioning. The distribution of treatment decisions did not differ between groups. Also, no difference was found on satisfaction with the decisions themselves, severity of the condition, social functioning, or preference for decision-making participation.[25]

Linking Preferences with Treatment Recommendations

The Department of Family Practice at the Medical College of Virginia, Virginia Commonwealth University, designed HealthTouch, a computerized health information system for health promotion and disease prevention for use in primary care.[26] Evaluated in a randomized clinical trial involving 29 primary care practices, HealthTouch was intended to supplement clinician involvement in patient-focused preventive services. As factors that contribute to variation in health and prevention outcomes, patient preferences regarding diet management, exercise routines, weight control strategies, and other practices[27] served as the basis for the customized computer recommendations for prevention. The preference assessment in HealthTouch is semantic in nature and does not rely on an explicit decision theoretic model.

Patients used a touch screen to answer 20 to 25 questions about personal and family history and about personal preferences that affect lifestyle. The system then generated patient-specific intervention criteria and education materials as well as clinicians' chart reminders, reports, and order forms that made it easier both to prescribe interventions and to document the interaction with the patient. The clinicians were able to modify the recommendations, further document patient preference to accept or decline implementation of the recommended activity, and order the interventions or screenings, if appropriate.

HealthTouch was incorporated into clinic practices in two ways: actively, by staff directing the patients to complete the survey, and passively, by placing the computers in the waiting area and allowing use based on patient choice. Regardless of the circumstances, follow-up surveys revealed that 77 percent of the patients who used HealthTouch received copies of their personalized health promotion recommendations, and of these patients 93 percent read the reports. Patients who were explicitly asked to complete the questionnaire were more likely to have had their practitioner discuss the report with them and to have completed suggested interventions than were patients who completed the survey on their own initiative. Nearly nine out of ten patients reported being very satisfied with HealthTouch and saw it as a personally valuable tool for their health.[26]

CURRENT STATE OF PREFERENCE ASSESSMENT AND COMPUTER TECHNOLOGY

Computer technology can support preference assessment and the communication and management of preference data. Most of the existing informatics applications demonstrate how computer technologies aid in preference assessment, employing computerized versions of decision analytic algorithms that follow decision theoretic principles but allow patients the privacy and time flexibility sometimes not feasible in a one-to-one interaction. Most of the existing computer applications for preferences are exploratory, research-based interventions and are not in general use.

These types of health informatics innovations can facilitate making patient preferences more accessible to clinicians.

Future Directions

Informatics initiatives to increase the accessibility of patient preferences in health care decision-making should address four major areas. Specific strategies include expanding the structure and function of the computer-based patient record to include the more subjective aspects of patient experience, including patient preferences. Research demonstration of the equivalence between computer-mediated preference elicitation and that directed by a skilled clinician may add persuasive power that increases diffusion. The next logical step for increasing the clinical accessibility of patient preferences is for informaticists to build tools to aid clinicians in interpreting the elicited patient preference data. Decision support systems could aid clinicians in the complex, cognitive processes linking patient preferences with scientific knowledge, clinical guidelines, and the realities of contemporary health care.

Informatics advances alone will not ensure that those making care decisions will be made mindful of patient preferences. Such a change in clinical practice will require increased clinician acceptance of shared decision-making philosophies and an increased ability to work with a more informed public. Changes in the incentives of health care delivery systems for particular decision-making styles or strategies are also needed.

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