

# What Is The Next Step in Patient Decision Support?

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*Patient decision support systems have a promising role in the delivery of health care. However, the best approach for further development of these systems is a matter of speculation. To help chart a course for further development of decision support systems, we consider the four traditional roles that patients play in the medical decision making process, the limitations that patients face in participating in each role and describe how contemporary systems address can facilitate successful decision making for each role. Because patients have a diversity of preferences for the role they play in decision making, we believe that the critical research question is how to make decision support systems robust enough to support a patient's desired role, whatever that role might be. By directing research in decision support systems in this fashion, we believe that they will achieve a larger patient audience and have increased value in the delivery of clinical care.*

## INTRODUCTION AND BACKGROUND

A recent meta-analysis has shown that patient decision support aids improve patients' knowledge and degree of participation in the medical decision making process<sup>1</sup>. This is compelling evidence for developing and using such systems. This paper examines ways to enhance existing methods for implementation of patient decision support, focusing on computer-based systems, in an effort to chart a course for future development of such systems. Decision aids are based on a heterogeneous set of conceptual theories and take diverse approaches to assisting patients with decisions. This paper reviews these approaches and suggests future directions for research. One approach to improve the usefulness of such systems is to tailor decision support to the patient's preferred decision making style. A second approach may be to focus decision support on helping patients overcome specific types of cognitive problems that can impair decision making for complex decisions that require patients to choose one of several risky alternatives.

Is the medical environment ready for patient decision support systems? Researchers and clinicians generally acknowledge that consideration of patient values is important in improving quality of care<sup>2,3</sup>. Computer decision support system research suggests that patients are eager to use such systems<sup>4</sup>. Moreover the readiness of patients for such systems is also suggested by wide spread use of the Internet for access to health related information<sup>5</sup>. Therefore the time

would appear to be ripe for further development of such systems.

However, a largely ignored aspect of decision support has been the role of patients meta-preferences for decision making styles. Surveys have shown that patient preferences for participation in clinical decisions vary greatly<sup>6,7</sup>. There are traditionally four roles that patients play in the medical decision making process<sup>8,9</sup>. Most decision support methods are designed to facilitate the patients' assumption of a role as the primary decision maker (e.g., full autonomy). However, most studies examining patients preferences for decision styles, suggest that only of minority patients wish to assume such authority. We discuss the types of roles that patients can play and the match between each role and current methodologies for decision support.

Patients also face common problems in making medical decisions that arise from the fact that few have practice choosing wisely from several risky alternatives. Many decision support systems require that the patient assume the role of a "decision analyst", weighing risk and benefit. Patients are presented with relevant data but receive little help with analysis and interpretation of that data. Moreover, many systems make patients responsible for understanding the impact of differences between their values and those of the "average" patient or of society and for the tailoring of care to suit their preferences. In such systems, although patients may learn what the recommended decision is for the typical patient, they may not learn the reasons underlying the recommendation or how to tailor care to best suit their own unique values.

## PATIENT PARTICIPATION ROLES

Patient interest in the role they play in decision making varies widely. The roles patients play vary in from taking no part in the decision process to seeking full control in the therapy selection. We review the four classical models of patient-provider roles in health care decisions: paternalistic, informed, collaborative, deliberative<sup>8,9</sup>. Recent studies have identified the proportions of patients wishing to assume each role and the demographic features associated with these preferences<sup>6,7</sup>.

### Paternalistic

In this model of clinical decision making, a patient believes that the health care provider has sufficient knowledge of both the decision domain and the

patient's values to make the appropriate decision. He or she vests the provider with complete authority for the decision. The decision domain consists of the possible options, outcomes and associated risks and benefits of each. The provider functions in the role of guardian who is responsible for overseeing the wellbeing of the patient. It requires limited involvement of the patient and it is assumed that the patient will be accepting and satisfied with whatever decision the provider chooses. It is up to the provider to know the patient's values and it is assumed that both parties share common goals in the selection of treatment. It is estimated that only about 3-8% of the patients seek a paternalistic role. Patients in this role generally are generally characterized by older age, male gender and a poor educational background<sup>6,7</sup>.

#### **Informed**

In this model, the provider functions as a domain expert from whom relevant information about the patient's condition and therapy options can be obtained. The patient seeks to be informed of their current disease state, the possible therapeutic options and the risks and benefits of each therapy. The provider plays little role in helping patients understand their values. The provider's goal is to ensure that the patient has an adequate educational base. It is assumed that the patient knows their own values and is skilled at integration of risk and benefit. Once the patient has been provided the necessary facts by the provider, the patient will be able to make the appropriate decision on their own exercising full autonomy. The health provider's role is to support this decision. The proportion of patients seeking an informed role ranges from 20-30%<sup>6,7</sup>.

#### **Collaborative**

In the collaborative role, the patient relies upon the health care provider to provide both facts and support in the decision making process. The provider functions in the role of adviser, attempting to elicit the patient's values for different health outcomes and assist the patient in selecting a therapy that is best matched to the patient's values. This role is similar to the informed model in that the provider is responsible for providing the necessary facts about the disease state and the available therapeutic options. In addition, the provider has the responsibility to help the patient discover their own values and understand how these relate to the decision.

It is different in that the provider must also assume the role often played by a decision analyst, such as in business consultations, where the provider's task is not only to educate the patient but to guide them through the decision making process. Value clarification is an essential part of the collaborative model. The proportion of patients desiring a collaborative role is believed to be 50-60%<sup>6,7</sup>. Like the informed group, these patients tend to be in a younger age group and have a strong educational background.

#### **Deliberative**

In this situation, the health care provider abandons objectivity. The provider's goal is to influence patients beliefs about the likelihood of outcomes and values so that they reflect what the provider feels are the patient's best interests. The provider functions in the role of friend or teacher in that the provider may suggest to the patient which decision they think best for the patient. Further, the provider may attempt to persuade the patient to change values the provider believes harmful or change mistaken beliefs about the likelihood of outcomes if the provider believes this to be best in the best interest of the patient. This differs from a collaborative model, where the provider primarily seeks to discover patients values and from the paternalistic model, in that authority is not delegated to the physician. For action to occur, both the patient and the provider must believe the chosen path is in the patients best interest. Studies show that the number of patients desiring a deliberative role range from 10-20%<sup>6,7</sup>. These patients tend to be in a younger age group, be highly educated and female gender.

### **PATIENT LIMITATIONS**

Although patients can play a very important role in the medical decision making process, they often face barriers to that participation. Understanding the decision domain, being able to manipulate quantitative information, developing problem solving skills, and understanding their values for different health outcomes are substantial and often difficult tasks for a patient to perform.

#### **Education**

Education can be a significant limitation to patients participating in the decision making process. Some patients lack the necessary background to understand all of the aspects of decision domain. The ability to understand complex medical processes and treatments or the associated risks and benefits is crucial to making an appropriate decision.

#### **Numeracy**

Numeracy is the construct that deals with an individual's ability to manipulate and understand basic probabilities and numerical concepts<sup>10</sup>. Just as education may limit the patient's ability to participate in the decision support activity, their facility with quantitative information might also be a barrier. Many of the methodologies require that the patient be responsible for the integration of the probabilities, understand short and long term effects on quality of life, and to make complex judgments in light of complex quantitative decision contexts.

#### **Problem Solving Skills**

The ability to formulate a problem and develop a strategy to solve it is crucial to the decision making process<sup>6</sup>. A patient must be able to obtain the necessary domain knowledge to make an appropriate

decision. Such skills are often difficult to master and often take time to develop.

### **Understanding Preferences**

There is also an assumption that patients understand the values they place on different health outcomes. Often it is difficult to understand exactly what a health state is like until one actually experiences it. Also, it can be hard for a patient to quantify their preference for a given health outcome without a formal assessment instrument. The values that patients perceive are also known to be affected by well-known biases<sup>11</sup>.

As the patient takes an increasing role in the decision making process, these issues become more important as the patient is required to perform more of the decision making task. Patients must be able to synthesize information about the decision and manipulate probabilities, quantify their values and apply their knowledge in order to identify the ideal decision. In order to provide decision support for the more independent patients, it is important that these issues be addressed.

## **CURRENT METHODOLOGIES**

Current decision support methods generally assume a single role for the patient in the decision making process. The collaborative role has received strong focus, with methods ranging from static literature to highly individualized computer-based interviews.

All of the methods attempt to address the issue of providing decision support, but few focus on helping the patient overcome limitations. Most do not relieve the burden of the patient of having to perform the role of decision analyst. That is, the patient is responsible for the synthesis and integration of the information and their values. In addition, they need to understand the implications that their values have in their decision and how their values compare to other patients facing the same decision.

### **Literature Synthesis**

Custom tailored informational brochures and handouts provide patients with descriptive and factual information about their condition and the therapy options. Such items might provide text or graphical explanations of the disease condition, the alternative therapies available and the probabilities of events.

Decision support literature is ideal for the patient who prefers to take an informed role. Patients are able to obtain information necessary to make the decision by reading the literature. The method assumes that the patient is able to understand and integrate all information presented in the literature and is able to determine their values for the different outcomes on their own. In addition, patients are expected to gain insight into the decision independently. This method does not address the issue of whether the patient has the necessary decision making skills, nor does it help

the patient in clarifying or identifying inconsistencies in their values. It also does not consider the needs of the patient preferring a collaborative or deliberative role in the decision making process.

### **Support Groups**

Support groups exist in many forms including public bulletin boards, email distribution lists, and online chatrooms. The bulletin boards allow patients to exchange typed messages via electronic news list or email digests. Online chat rooms allow patients to interact with each other or health care providers using a computer interface.

It has been shown that the use of public bulletin boards and anonymous question and answer modules increases the confidence in decisions, but does not improve decision making skills<sup>12</sup>. The perception of being supported in the decision making process may be just as important as the decision support itself. Support group methods are best suited for the patient who takes a deliberative role in the decision making process. The patient is responsible for asking questions or finding answers about their medical condition and the therapeutic options available to them. There is also no way for the direct elicitation of values or explanation of their impact on the decision.

Support groups fail to address the issue of value clarification. The values that patients quantify on their own may not be helpful. Probability estimates from peers may be also be biased since patients on the web tend to be more severely ill<sup>13</sup>. This method is consistent with all patient roles except paternalistic.

### **Decision Boards**

Decision Boards are generally large boards or posters that display decision alternatives with graphical feedback on outcome probabilities<sup>14</sup>. These displays allow the patient to consider a simple decision and visualize changing probabilities for different events or outcomes. Although they are relatively simple to create, they can only be used for simple decisions due to the limitations of space and the materials used. The method is objective and provides support for numeracy through probability displays. Decision boards are best used for the patient who seeks the role as an informed decision maker. If the physician wishes to adopt a different strategy, this method may result in conflicts, as the metric assumes the alternatives are available to the patient, if they so desire.

The boards provide information to the patient, but require that the patient be able to integrate the risk/benefit profile of each of the options and understand how these tradeoffs affect quality of life over different time periods. Because the boards lack interactivity, patients who desire a collaborative role in the decision making process are unable to obtain means to elicit values for health outcomes or gain insight into how those values impact the decision.

### **Meta-analytic Shared Decision Support**

Meta-analytic decision support strategies are an enhancement of decision boards. This approach combines decision board strategies for communication about probabilities with a value clarification exercise. In a clarification exercise, the patient uses disease symptom scales to ascertain their current level of symptoms, and then, in the critical step for the approach, determines the degree of relief desired by specifying the maximum acceptable level of symptoms. Meta-analytic data summaries from randomized trials are used to determine the probability of the patient achieving their desired level of relief with a given treatment alternative. This is displayed in a decision board like format along with risks of complications. The patient uses this information, to weigh risks vs. benefits<sup>15</sup>. Like Decision Boards, this method is designed to allow patients to assume the role of an informed decision maker. It might also serve as an introduction for further conversations with physicians based on either collaborative or deliberative models.

### **Shared Decision Making Programs**

In shared decision making, patients are presented the risks and benefits of medical treatments via multimedia computer programs<sup>16</sup>. These systems can be expensive and difficult to administer, with the content quickly becoming outdated. The primary difference between shared decision making programs and decision boards, is that, in addition to outcome descriptions and display of probabilities, the programs present model patients who have adopted certain decision strategies. Model patients, in side-by-side presentations of decision alternatives, describe their decision strategies and rationale for particular choices. Each patient argues for their own decision. While the overall presentation is balanced, each alternative has an advocate who plays the role of a friend or advisor. Thus shared decision making programs focus much more on a deliberative style.

Of course, not every strategy is presented and defended—only the strategies that the developers feel are reasonable for the patient. These programs also attempt to address issues of numeracy. However, they don't attempt formal value clarification exercises. Shared decision making programs support the informed model and can serve as introductions in collaborative and deliberative models. Physicians attempting to use such models after exposure of the patient to the system would need to be aware of how values are described in each program.

### **Individualized Decision Support Programs**

These programs attempt to elicit preferences from patients and generate treatment recommendations based integration of patient values with a decision model. The approach taken in decision analytical decision support programs is similar to the role that the physician plays in collaborative models. The program helps patients discover their preferences and

then informs them of the consequences of such. This approach remains largely experimental at this time, though proof-in-concept studies have been undertaken<sup>17,18</sup>.

This method supports all decision making models. As a test that measures patients preferences, it could enhance physicians ability to understand and tailor preferences when the patient seeks a more passive role. If the patient wishes to assume the role of informed decision maker, such systems can generate insights for patients into implications of their values. Use of a computer tool to conduct this exploration might allow patients to retain more autonomy than having physicians assume this role. Reports from such systems also could support collaborative and deliberate decision models. By providing patients preference data and decision model predictions on the appropriateness of specific types of therapy given their preferences, these systems may reduce the time required for and improve the quality of patient-provider interactions using this decision making style.

## **FUTURE DIRECTIONS**

We believe that there are two clear ways to improve patient-oriented decision support systems. The first is to focus on assisting patients with the limitations they frequently face when making a medical decision: education, quantitative manipulations, problem solving skills and preference valuation and comparisons. Second, these systems should be able to accommodate several, if not all four of the patient roles.

There are four traditional roles that patients play in the medical decision making process. Several decision support approaches have been developed for patients facing therapeutic decisions, but all are targeted at specific patient participation roles. In addition, many of the decision support methods fail to address the most common problems faced by patients making difficult medical decisions. While the above methods attempt to provide education about the decision domain and help the patient better understand the risks and benefits of the alternative treatments, none address the issue of assisting the patient in integration of long term impacts, such as aspects of quality of life, or on generating insight into the impact of the patient's values on the decision. Examples of this would be to display to the patient their values relative to a similar population or how the decision recommendation changes with the assessment of each of their preferences. This could provide insight and help reassure the patient that their values for health states are consistent with other patients.

Future decision support efforts should consider the decision-making role the patient seeks. Not all patients desire the same level of participation in the

medical decision making process. Because of this, a decision support methodology which is custom tailored for a specific patient role is only appropriate for a subset of patients. This can lead to the alienation of patients who prefer certain roles not addressed by popular methods. In addition, by providing a single method which can support all patient roles, one can greatly reduce the cost to develop and maintain decision support systems while providing support to the entire patient population.

A solution would be to develop a computer-based system which has the ability to not only educate the patient and elicit utilities, but assist the patient in exploring the decision space and providing insight and explanations about the impact of the patient's values on the decision. We believe that the use of intelligent methods in decision support systems will allow for the system to not only custom tailor the dialogue and recommendation for a particular patient, but also provide a means to individualize the level of interaction to the role that the patient prefers to take in the decision making process. This should allow for such systems to not only increase the quality of support for an individual patient, but allow for the reuse of a single system for patients that wish to function in different participatory roles.

Such a system could also be designed to function in accordance with the individual patient's preferred level of involvement, while using the same model and base of knowledge. This could expand the intended audience of decision support tools, improve the consistency of information and reduce the time and cost of implementation. By extending contemporary decision support systems in these ways, it should be possible to increase the value and acceptance of such systems in clinical care and expand the patient audience to which they are useful.

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