Shared Decision Making in Clinical Medicine: Past Research and Future Directions
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Content: Shared medical decision making is a process by which patients and providers consider outcome probabilities and patient preferences and reach a health care decision based on mutual agreement. Shared decision making is best used for problems involving medical uncertainty. During the process the provider-patient dyad considers treatment options and consequences and explores the fit of expected benefits and consequences of treatment with patient preferences for various outcomes. This paper reviews the literature on shared medical decision making. Several questions are considered. Although several studies suggest that patients do not want to be involved in decision making, these studies typically fail to separate decisions about technical aspects of treatment from preferences for outcomes. There is considerable evidence that patients want to be consulted about the impact of treatment. Studies on the acceptability of shared decision making for physicians have produced inconsistent results. Shared decision making is more acceptable to younger and better-educated patients. It remains unclear whether shared decision making requires expensive video presentations or whether the same results can be obtained with simpler methods, such as the decision board. We conclude that shared medical decision making is an important development in health care. More research is necessary to identify the effects of shared decision making on patient satisfaction and health outcomes. Further, more research is necessary in order to evaluate the most effective methods for engaging patients in decisions about their own health care.


Over the last decades, there has been an increasing emphasis on patient participation in medical decision making. An alternative to the paternalistic model in which the physician makes all treatment decisions is "shared decision making." Shared decision making must not be confused with obtaining informed consent from a patient. While ethical guidelines mandate informed consent, especially when a recommendation involves a potentially harmful intervention, shared decision making goes several steps further. Beyond presenting the patient with facts about a procedure, shared decision making is a process by which doctor and patient consider available information about the medical problem in question, including treatment options and consequences, and then consider how these fit with the patient's preferences for health states and outcomes. After considering the options, a treatment decision is made based on mutual agreement. Several conditions must be met for shared decision making to occur. First, the atmosphere must be conducive to active patient participation. The attending physician must make patients feel that their contributions are valued. Patients in turn need to be frank about their preferences and goals for treatment. The physician then helps the patient determine how these goals and preferences fit with the available treatment options and a shared decision is reached.

Several medical associations now recommend shared decision making in relation to preventive services, in part reflecting that preventive screening often involves complex tradeoffs between risks and benefits. The American Cancer Society, the American Urological Association, and the American College of Physicians recommend shared decision making in their clinical practice guidelines for prostate cancer screening. Similarly, the American Gastroenterological Association, in collaboration with the Agency for Health Policy and Research, recommends shared decision making in screening for and choosing among alternative approaches to screening for colorectal cancer. The Na-

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Why Shared Decision Making?

The classic view of the sick-role, as conceptualized by Parsons, sees the patient as exempted from his or her societal role by a physician. A sick patient attains this privilege by submitting to the physician's directives. Following the prescribed course of treatment is expected to bring about relief and limit the time spent in the sick-role. According to this model, which has predominated medical treatment for many decades, the physician is dominant and autonomous and bears sole responsibility for making treatment decisions. The physician is viewed as capable of discerning and implementing patient preferences.

A number of developments suggest that the paternalistic model is no longer viable in the practice of clinical medicine. First, the standard of informed consent required for medical treatment has changed. For many years the U.S. Supreme Court tacitly reinforced paternalism by calling on physicians as expert witnesses in informed-consent lawsuits. Hence, physicians decided how much information a physician should disclose to patients. More recently, laymen have been consulted in lawsuits to determine whether physicians provided enough information to patients. This presents a considerable shift in respecting the autonomy of the patient and moving away from the physician as an all-knowing individual who can decide what information is suited for the patient. Treatment should occur only after a patient is thoroughly informed about the implications of the choice and has agreed to the procedure on the basis of this information. Second, the public is becoming increasingly educated and skeptical of physicians. Medicine is facing a general crisis of confidence because of failure to share knowledge, and the patients' rights movement has sought to assert the patient's prerogatives. The Internet has become a powerful medium for patients to obtain information about medical problems and treatments as well as about alternatives to traditional medicine. Internet discussion groups serve to disseminate information among individuals as well as to provide patients access to social support. Since the Internet cuts across local and national boundaries, patients can obtain information about a wide range of treatments that may or may not be endorsed by their physicians. The wider availability of information forces physicians to be more comprehensive in discussing available treatment options and empowers the patients. The downside to the wide availability of information is that patients may not always be good consumers of medical science and consequently may seek treatments for which efficacy is not clearly established. In addition, Web sites offering information to patients are not always accurate in their recommendations.

Evidence-based reviews often fail to identify one treatment as clearly superior to all alternatives. Typically many treatment options exist, and no choice is clearly the best. Each alternative brings trade-offs between benefits and risks. While some interventions may have long-term benefits, these benefits may come at the expense of reductions in immediate quality of life. For example, a patient with mild hypertension may experience no symptoms now, but taking antihypertensive pharmacotherapy may cause symptoms in the form of side effects. The promise of this therapy is that it may lead to overall greater life expectancy by reducing the long-term morbidity associated with the consequences of hypertension. However, the gain of taking antihypertensive medication is delayed and probabilistic since reduced blood pressure does not necessarily imply clear long-term health benefits.

Wennberg and colleagues have observed wide variations in medical treatments that are given to patients in different regions of the United States, including highly variable rates of surgery for different conditions. Two of the primary reasons cited for these variations are hospital capacities and scientific uncertainty as to what constitutes appropriate treatment. Hospitals with greater hospital capacity do more procedures. Physicians frequently disagree on what constitutes appropriate treatment. Panel reviews of surgical case descriptions suggest that many surgeries are not indicated. When given the same case descriptions of patients, United States physicians were more than twice as likely to say surgery was appropriate in comparison with their colleagues in the United Kingdom. Similarly, high rates of unnecessarily radical surgery for breast cancer by surgeons in Italy have been reported.

Variations in the use of prostatectomy to treat benign urinary tract obstructions among men suggest that surgeons disagree over whether the surgery actually results in a reduction of symptoms. While physicians frequently disagree among themselves about the efficacy of a given treatment approach, they are typically quite confident that their individual treatment decisions are correct. This has been described as the "micro-certainty, macro-uncertainty" phenomenon. An examination of symptom status following prostatectomy reveals that, for patients who experienced mild to moderate symptoms prior to surgery, changes in symptoms following treatment were negligible. However, many cases experienced negative consequences following surgery, such as postsurgical infections, impotence, incontinence, and the need for additional surgery.

Patients and physicians often expect more than a given therapy can actually accomplish. In asymptomatic prostatism the patient could postpone surgery and engage in "watchful waiting," keeping the alternative of...
surgery open if necessary. Given the uncertainty of medical treatment outcomes and the availability of treatment options for many if not most medical problems, the responsibility for choosing a treatment should be shared by both the physician and the patient. The evaluation of available options should be based on the individual preferences for health states and patient outcomes. A patient brings information to a discussion about treatment options that a physician cannot know. Individuals vary in their preferences for health states, tolerances for pain and discomfort, and long-term outlooks. This information, which is crucial to choosing a specific treatment approach, is known by the individual patient but could not be known by a physician without discussion. Concerning options for the treatment of laryngeal cancer, McNeil and colleagues found that some patients placed greater value on proximal years of life with more quality, rather than more years of life but with less quality. In a recent study of the health values of hospitalized patients over the age of 80, one of the most important findings was the large amount of variance in patients' preferences for health states. While some patients were unwilling to trade any time alive for excellent health, others were willing to live as little as 6 weeks in excellent health instead of 1 year in their state of health at the time of assessment. Wennerberg and colleagues argue that the "right" rates of surgical procedures could be found if medical decisions are made in collaboration between patient and doctor and ultimately reflect the personal preferences of the patient.

Treatment decisions should result in the most desirable outcome for the patient. Meeting this goal requires the active participation and engagement of both the physician and the patient. The shared approach to medical decision making is advantageous for several reasons. First, shared decision making allows for better data collection on the part of the physician as well as the patient. Second, it forces the physician to present and consider all treatment alternatives. Hence, the quality of decisions is enhanced, and compliance is increased, since patients can feel that they participated in the decision-making process. A passive patient merely following directions from a physician may be less prepared to translate a treatment plan into a "workable daily routine of disease management." In a study of hypertensive patients, Schulman found that those who were actively engaged in their treatment also had better outcomes. Brody and colleagues and Lerman and colleagues found that patients who engaged in medical decision making had a greater sense of personal control, lower levels of concern about their disease, and were more satisfied with treatment. In a study of coronary bypass patients, individuals with a greater sense of control and more involvement in their treatment had shorter hospital stays following surgery. Nonetheless, there are clear limitations to shared decision making. In medical emergencies it may not be viable to consult patients about their treatment preferences. Similarly, not all medical problems are suitable for shared decision making. For example, in the case of acute appendicitis, the only reasonable treatment is surgical appendectomy; thus shared decision making will not measurably affect treatment choices.

**Do Patients Want to Engage in Shared Medical Decision Making?**

A central question to the shared decision-making paradigm is whether patients actually want to participate in medical decision making. Several studies have addressed this question, and results of these studies have been mixed. A summary of these results appears in Table 1. Cassileth and colleagues examined the extent to which cancer patients with varied diagnoses wanted to participate in treatment decisions. Most participants indicated a desire to participate in treatment decisions. However, clear age differences emerged. Among those aged 20–39 years, 87% preferred to participate in treatment decisions. This declined to 62% among those aged 40–59 years and to 51% among those aged 60 years or more. These age-related findings remained after adjusting for differences in education. Patients who felt hopeless were less likely to want to participate in treatment decisions. Strull and colleagues found that among a sample of older (mean age = 59 years) hypertensive outpatients, only 19% wanted to share decision making with their physician. Nonetheless, physicians in the study were found to be poor judges of their patients' needs for information and discussion about treatment. Forty-one percent of participants would have preferred more information than was provided. In 28% of physician-patient encounters, the physician underestimated the patients' desire for discussion about treatment, whereas physicians overestimated it in only 13% of encounters. Pendleton and House found that low-income inner-city diabetic outpatients had little interest in medical decision making. However, the psychometric properties of their measure were not reported, and the study included only 47 subjects. Similarly, Ende et al found low levels of interest in medical decision making among a sample of general practice outpatients. The authors constructed a new scale to measure desire to participate. Although the scale had adequate reliability, the validity of the measure was not impressive. Decision-making scores derived from this scale showed a correlation of only 0.54 with an item directly assessing patient desire to participate in decision making. However, consistent with findings from previous studies, these authors found that younger patients had a greater desire to participate in treatment decision making than
older patients. Overall, patient demographics and health status were able to account for only 19% of the variance in desire to participate in treatment decisions. This suggests that there are other factors that contribute to understanding who wants to share decision making with physicians.

Using the same scale, Ende and colleagues examined how preferences for decision making might differ when the patients are themselves physicians. Although the findings consistently indicated statistically significant greater preferences for decision making among physicians, compared with nonphysician controls, the authors interpreted these differences as of minor importance. Consequently, they concluded that if physicians do not have an overwhelming interest in clinical decision making, this may suggest that being ill implies wanting to surrender decision-making responsibility to the attending physician. In both studies, the authors found that overall desire to participate in clinical decision making declined as the medical problem in question became more serious.

Although desire to participate in decision making may decline as a function of disease severity, other researchers have shown that patients want to be involved in decisions about invasive, potentially risky interventions. Mazur and Hickam examined the extent to which patients desired shared decision making when faced with the possibility of an invasive medical procedure such as surgery. Most participants (68%) indicated a preference for shared decision making. Similar to other studies, these authors also found that interest in decision making declined with age. A limitation of this study is that participants were judging hypothetical scenarios.

In another study, informal interviews with 12 hospitalized patients by nursing researchers suggested that patients were not interested in shared decision making. Patients overwhelmingly indicated a desire to simply comply with their physician's orders in the hope of avoiding negative repercussions from hospital staff. However, these results may be explained by the fact that decision making had already occurred once the patients were being treated in a hospital.

Given the findings from the above studies, it is not clear whether the shared decision-making paradigm is, in fact, feasible for all patients. Deber argues that many studies fail to make a distinction between problem solving and decision making. In the first instance, treatment of a medical problem requires diagnosis and a determination of treatment alternatives, which in turn require a high degree of technical expertise. These tasks, which require problem solving, are the

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Table 1. Patient interest in shared decision making

<table>
<thead>
<tr>
<th>Authors</th>
<th>Year</th>
<th>Type of study/design</th>
<th>Main findings</th>
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<tbody>
<tr>
<td>Cassileth, Zupis, Sutton-Smith, &amp; March</td>
<td>1980</td>
<td>Questionnaire completed by 256 cancer patients at a university hospital</td>
<td>'Patient [Prefers] participating in decisions'</td>
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<td></td>
<td></td>
<td></td>
<td>Overall—62.5%</td>
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<td>Aged 20-39—87%</td>
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<td>Aged 40-59—62%</td>
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<td></td>
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<td></td>
<td>Aged 60+—51%</td>
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<td>Strull, Lo, &amp; Charles</td>
<td>1984</td>
<td>Questionnaire completed by 210 patients with hypertension in three separate clinics</td>
<td>Preferences for roles in decision making:</td>
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<td></td>
<td></td>
<td></td>
<td>Physician should be primary decision maker—78%</td>
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<td></td>
<td></td>
<td></td>
<td>Decision should be shared—19%</td>
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<td></td>
<td></td>
<td></td>
<td>Patient should be primary decision maker—3%</td>
</tr>
<tr>
<td>Pendleton &amp; House</td>
<td>1984</td>
<td>Questionnaire completed by 47 inner-city diabetic outpatients</td>
<td>Mean composite score for questionnaire = 3.9 (Range 0-10; higher scores indicate greater information and participation preferences)</td>
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<tr>
<td></td>
<td></td>
<td></td>
<td>(Range 0-100: 0 indicates very low preference for decision making, 100 indicates very high preference, 50 indicates neutral attitude)</td>
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<tr>
<td>Ende, Kazis, Ash, &amp; Moskowitz</td>
<td>1989</td>
<td>Questionnaire completed by 312 patients at a university hospital primary care clinic</td>
<td>Mean composite score for decision making = 40.6 (See previous study by same authors for reference range)</td>
</tr>
<tr>
<td>Ende, Kazis, &amp; Moskowitz</td>
<td>1990</td>
<td>Questionnaire completed by 151 physicians attending a continuing medical education course</td>
<td>Patients showed little interest in decision making and were focused on 'staving out of trouble' and 'toeing the line'</td>
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<tr>
<td>Waterworth &amp; Luker</td>
<td>1990</td>
<td>Informal conversational interviews with 12 hospitalized patients</td>
<td>Mean response to problem-solving tasks = 1.8</td>
</tr>
<tr>
<td>Deber, Kraetschmer, &amp; Irvine</td>
<td>1996</td>
<td>Questionnaire completed by 300 patients scheduled to receive an angiogram</td>
<td>Mean response to decision-making tasks = 3.1 (Range 1 (doctor alone) to 5 (you [patient] alone); 3 = doctor and you equally)</td>
</tr>
<tr>
<td>Mazur &amp; Hickam</td>
<td>1997</td>
<td>Structured interview completed by 467 general practice outpatients at a university VA hospital</td>
<td>'Whom do you prefer to make the decision?' Shared authority—68.1%</td>
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<tr>
<td></td>
<td></td>
<td></td>
<td>Physician-based authority—21.4%</td>
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<td></td>
<td></td>
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<td>Patient-based authority—10.5%</td>
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domain of the physician and precede decision making. Patients are unable to diagnose and determine treatment alternatives since they likely lack the same knowledge base as the physician. The studies that found little interest in shared decision making \(^{35-36}\) employed questionnaires that did not make clear distinctions between problem solving and decision making. Hence, Deber concludes, it is not surprising that these studies find little support for shared decision making, since patients are unwilling to take on tasks for which they are not qualified. Using a scale that differentiated between problem solving and decision making, Deber found strong support for the hypothesis that patients want to leave problem-solving tasks almost exclusively to the physician, but decision making should be shared.\(^ {40}\)

Alternately, Kaplan\(^ {41}\) argues that the problem is one of distinguishing between treatment outcomes, the choice of which should be in the control of the patient, and means to these outcomes, which depend on advice from the physician. Choosing among treatment alternatives is ultimately a choice of outcomes, hence the physician’s role is to present and discuss with the patient different means (treatment options), for which evidence suggests that specific outcomes will be achieved.

Studies that do not find patient interest in shared decision making rarely recognize that most lay persons are unaware that medicine is an inexact science and that there are multiple possible treatments for most problems. Patients tend to believe that their physician has prescribed either the only available treatment or has chosen the best treatment from those available. Thus, it may be necessary to educate patients about how choices for treatment relate to their personal preferences for health states and can affect treatment outcomes.\(^ {42}\)

While the evidence suggests that many patients prefer shared decision making, it remains unclear why some patients prefer physicians to make decisions for them. Younger age appears to be the most consistent predictor of desire to actively participate in medical treatment decisions. In addition, patients with more education tend to have a stronger preference for participation in clinical decisions.\(^ {39}\) However, age and education may have limited explanatory power. Therefore, it is important to consider other factors that may account for patients’ limited interest in shared decision making.

The process of weighing risks and benefits of a medical intervention with personal preferences for health states and outcomes is usually novel to the patient.\(^ {43}\) Patients may be intimidated by the complexity of medical decision making. Anxiety over making the “right” decision may leave the patient wanting to surrender decision making to the physician. However, the relationship between a patient’s self-efficacy in a clinical encounter and interest in shared decision making has to be determined empirically. In addition, it is not clear how language and cultural barriers interact with shared decision making. While evidence suggests that medical practitioners can be taught how to work most effectively with persons from different cultural backgrounds,\(^ {44}\) this variable has thus far not received any consideration in research related to shared decision making. At the most basic level, implementing shared decision making will pose additional challenges when physician and patient do not share a common primary language. Different cultures also have varying approaches to authority, with some cultures being more deferential than others.

Researchers need to identify methods to increase a patient’s participation independent of the physician. The argument that there is insufficient patient interest to pursue this paradigm is fundamentally flawed. It ignores that decisions, which will affect treatment outcomes, must reflect a patient’s personal preferences and that physicians cannot discern these unless they actively engage with the patient and assess beliefs and expectations.

**Do Physicians Want to Engage in Shared Medical Decision Making?**

A patient’s wish to participate in clinical decision making will have little impact if the physician is not open to the process. Despite the increasing shift toward patient-centered medicine in recent years,\(^ {45}\) we were unable to locate studies that directly surveyed large samples of physicians regarding their views on shared decision making. While academic medicine espouses shared decision making as the clinical ideal, it is unclear how nonacademic physicians are inclined toward this paradigm. Some physicians may feel threatened by patient empowerment.\(^ {46}\) Abramovitch and Schwartz\(^ {47}\) note that a scientific approach to medicine based on limited dialogue with the patient may be a way to avoid highly emotionally charged situations that often arise as a result of medical diagnosis. Similarly, Eraker and Politser\(^ {48}\) find that physicians are often reluctant to disclose information relevant to making uncertain choices. This is especially true when these choices involve trade-offs among risk, disability, and death. A recent study by Kaplan and colleagues\(^ {48}\) found that physicians who encouraged shared decision making had previous training in primary care or in interviewing skills, lower patient volume in their medical practices, and more satisfaction with the extent of their personal autonomy. The authors suggest that cost-containment measures that increase the number of patients a physician has to see, may in fact compromise the effectiveness of care by discouraging shared decision making, which may ultimately lead to higher health care costs.

A further issue is that many physicians may lack the necessary communication skills to engage patients in
The primary purpose of the intervention was to help degree to which participants controlled their medical physicians. Participants, drawn from a peptic ulcer was significantly negatively correlated with HbA1c values. tion from the physician than the control group. The and providing patients with balanced reviews of treat mental subjects were much more active in their en areas: increasing a patient to confront the complexit between ph physicians can present the patient with balanced re

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How Is Shared Decision Making Implemented and What Are the Results?
The basic preconditions to shared decision making between physician and patient have been outlined, but meeting these conditions may not always prove sufficient to confront the complexity of medical decision making. To date, limited research has focused on two areas: increasing a patient’s ability to engage physicians in a dialogue that facilitates shared decision making and providing patients with balanced reviews of treatment options and consequences.

Greenfield et al designed an intervention to facilitate patient participation in medical decision making. The primary purpose of the intervention was to help patients become more active in their encounters with physicians. Participants, drawn from a peptic ulcer clinic, were randomized to one of two conditions. In the experimental condition, participants were taught how to elicit more information, to recognize relevant medical decisions, and to negotiate these decisions with the physician. The intervention was delivered in a 20-minute session immediately preceding the patient’s visit with the physician. Issues relevant to the particular individual were identified through chart review. Participants assigned to the control group received didactic information regarding peptic ulcers. Results showed that, compared with the control group, the experimental patients were more involved in their medical encounters, were more assertive with their physicians, and elicited more information from the physician. Controlling for baseline status, experimental participants showed fewer role limitations than participants in the control group at follow-up. Experimental participants showed greater preferences for medical participation and had significantly more positive affective interactions with their physicians than the control group. The experimental group also showed an improvement in subjective well-being even though levels of pain were rated the same between the groups at follow-up. The authors found no evidence that increased patient involvement disrupted the relationship between physician and patient.

A subsequent follow-up study examined how the intervention affected biological indicators of health. For this purpose the authors selected diabetic patients as the target of the intervention. Glycosylated hemoglobin (HbA1c) values are easily obtained and provide an indication of a patient’s glycemic control over a 6- to 8-week period, with lower values indicating better control. Participants randomized to the experimental condition received two 20-minute interventions during two respective physician’s visits. They were taught how to increase information seeking and how to participate in decision making with the physician. Prior to meeting with the physician, issues that could be discussed were clarified and the participants were taught negotiating skills. The control group received standardized educational materials pertaining to diabetes. Follow-up results showed a significant decrease in HbA1c values from baseline among the experimental group but no change in the control group. Participants in the experimental group also lost fewer days of work due to illness, but there were no differences in patient satisfaction or diabetes knowledge. While the length of medical encounters did not vary between the two groups, experimental subjects were much more active in their encounters, asked more questions, and controlled the encounter more frequently than the control group. The experimental group also obtained more information from the physician than the control group. The degree to which participants controlled their medical encounters and the amount of information they sought was significantly negatively correlated with HbA1c values.
Kasper and colleagues described an alternative approach to facilitating shared decision making. Shared decision-making programs (SDPs) utilizing electronic media take the job of presenting information away from the physician. Instead, information on treatment choices and their probable implications are presented with interactive videodisc or videotape. Once the physician makes a diagnosis, the patient views an impartial, carefully balanced program that outlines treatment options and how these will affect the patient’s future quality of life. When using interactive videodiscs, the presentation is tailored toward general treatment preferences indicated by the patient. In an effort to increase patients’ vicarious understanding of their medical problem and the available options, some information is presented using previous patients who were faced with similar decisions. The patients provide the viewer with glimpses into how they weighed their options and balanced these with their personal treatment preferences.

SDPs are developed by a foundation for medical decision making. To begin, a team develops a specification of the targeted medical problem and the available treatment options. Program content is determined by individuals from academic medicine through literature review and metaanalysis. Using a series of focus groups, the team defines the structure of the decision-making problem, develops a program content summary, conducts an external content review, analyzes and resolves issues raised, designs the program, and develops supporting documentation. Programs are updated as needed, and a team is appointed to monitor developments that would necessitate revisions.

Barry et al evaluated patient reactions to an SDP developed for patients diagnosed with benign prostatism. Most patients found that the SDP presented the right amount of information and was appropriate in length. The presentation was seen as clear and balanced. The authors found that the use of the SDP resulted in a reduction of surgery and an increase in “watchful waiting,” whereby patients chose to postpone surgery since symptoms were minimal. Flood and colleagues conducted two studies to examine the impact of an SDP for patients considering a prostate-specific antigen (PSA) test to screen for prostate cancer. Compared with patients who viewed either a control videotape (Study 1) or no videotape (Study 2), patients who viewed the SDP subsequently had more accurate knowledge about the PSA test and prostate cancer and were also more likely to choose “watchful waiting” as a treatment option for prostate cancer. Patients who viewed the SDP in Study 2 were also more likely to decline having a PSA test, compared with patients who did not view the video.

The findings of a study evaluating an SDP developed for patients suffering from ischemic heart disease were not as straightforward. While the SDP helped 44% of undecided patients make a treatment choice and increased the patients’ confidence in their decisions, a significant proportion of patients (41%) indicated greater anxiety about their treatment decisions. Greater increases in anxiety were found among ethnic minority patients. Seventy-seven percent of the sample cited their physician as the most important factor in treatment decision making.

Increased anxiety among some patients raises the question as to the degree of physician involvement in discussing treatment options after patients viewed the videodisc. Forty-four out of sixty patients (73%) had already received a physician recommendation prior to viewing the SDP. As Deber points out, the SDPs are a useful solution to the limited-time dilemma faced by many physicians in presenting information about treatment options. However, it remains unclear when a patient should view the SDP and whether physicians should make treatment suggestions prior to viewing an SDP. Future research should test SDPs with and without a subsequent consultation with a physician. This would permit the separation of the effect of the SDP from the effect of SDP plus physician encounter.

Decision boards are another method for facilitating shared decision making. Levine and colleagues first described the development of such a decision aid for use with women facing the choice of adjuvant chemotherapy for breast cancer following surgery. While postsurgical chemotherapy results in a decrease in cancer recurrence, this overall modest benefit comes at the cost of serious side effects during treatment. The decision board separated making a choice into three components: (1) treatment choices, (2) chance of outcome, and (3) outcome. In this case there were two treatment choices: adjuvant chemotherapy or no chemotherapy. The chances of outcome were represented in percentages, illustrated with pie charts; and the outcomes were “cancer free” or “cancer came back.” In concordance with the practice of clinical oncologists, the authors chose to frame outcomes negatively, focusing on cancer recurrence instead of cures. Patients found the decision aid easy to understand, and its use helped most patients ask additional questions about the choices they were facing. Moreover, most patients felt that the decision board helped them make a decision.

Whelan and colleagues used a sequential design to compare women faced with the choice of breast irradiation post lumpectomy using a decision board or receiving “usual care.” The first group of patients received usual care consisting of a consultation with a physician. The second group also received a consultation with the physician, but this consultation included the use of a decision board similar to the one described above. The average length of the consultation with a physician was the same regardless of use of the decision board. In addition, patients in both groups made similar choices, most favoring irradiation. However,
there were important differences between the two groups. First, patients in the decision-board group showed a greater understanding of the therapeutic limitations of irradiation. Second, while 97% of the patients in the decision-board group felt that they were offered a treatment choice, only 70% of patients in the usual-care group mirrored this feeling. As in the earlier study, patients whose consultation involved the decision board felt that it stimulated them to think of additional questions and provided significant assistance in making a decision.

Decision boards present a viable alternative method for facilitating shared decision making. One considerable advantage over the SDPs described by Kasper et al15 is their cost. The production costs of an SDP were estimated at $750,000 by the authors. This is a considerable investment that places clear limitations on their use. Nonetheless, while decision boards provide a much cheaper alternative to SDPs, they are also limited in the amount of information they can provide without becoming cumbersome. The applications described above dealt with the choice of receiving a therapy or not. While the decision boards were effective for these purposes, it may be that decision boards are most useful for problems in which there are only a few alternative choices.

Summary and Future Directions

There are a number of unresolved questions related to the implementation of shared decision making. The evidence regarding patient interest in decision making is mixed. Some studies have found little interest in shared decision making, while others find most patients desiring some control over decision making. The distinction between technical problem-solving issues and decisions that pertain to treatment outcomes is crucial in explaining the reluctance some patients have, but further research is needed to explore other causative factors. None of the studies reviewed have examined self-efficacy or locus of control and how this may be related to the desire to participate in medical decision making. The consistent finding that older patients are less interested in shared decision making suggests a cohort effect. Finding ways to increase older patients' ability and willingness to engage in shared decision making will be very important as overall life expectancy increases and people are faced with more medical problems resulting from longer life spans.

Several methods for facilitating shared decision making have been developed. To date, the studies by Greenfield and colleagues26,51 are the only ones that have employed randomized, prospective experimental designs. These studies demonstrated that patients' attitudes in medical encounters are readily changed and that increasing patient participation has considerable positive effect on treatment outcomes. Further research needs to apply similar methods to other types of diseases and chronic illnesses to determine whether such efficacy generalizes to other medical problems. An important factor that has received no attention is the degree to which such interventions are efficacious for members of different cultural groups. In a country as diverse as the United States, it is no longer sufficient to focus research only on members of the dominant cultural group. Attitudes and customs of some cultures may represent barriers to shared decision making, and research needs to determine whether this is the case and what can be done to cope with these issues.

SDPs and decision boards represent important developments in providing patients with balanced presentations of information pertinent to making decisions about medical treatment. However, none of the studies examining the use of SDPs or decision boards has used randomized experimental designs. The conclusions that can be drawn from these studies are therefore limited. Results from randomized trials could clarify the effect of using decision aids on a variety of patient variables and outcome measures. These include the patient's quality of life and mortality; the extent to which the patient is confident in the decision made and satisfied with the care received; the ability and willingness of the patient to follow a chosen course of treatment; and lastly, the cost of treatment. It is unclear as of yet whether shared decision making will truly lead to a reduction in rates of surgery, as suggested by Wennberg and colleagues.17

Further research is needed to determine the best sequence for using decision aids in reaching a treatment decision. Research is also needed on other applications for these types of decision aids. To date, these tools have focused on helping make decisions about diseases that have a relatively immediate threat of mortality. Many medical problems and their treatments are not anchored by impending mortality. Research needs to explore the use of decision aids for such diseases. Moreover, many older patients have multiple problems. These problems are often chronic and the treatment of one condition may affect other chronic health conditions. Future work should address these common decision problems for older adults.

Another problem that deserves further study is the involvement of family and friends in the decision process. To date, most studies have assumed that patients and physicians make most decisions. In fact, family and friends are frequently important influences on many patients. Future research must systematically investigate the integration of these contributors.

Medical decision making under stress is poorly understood. Little is known about how choices may be affected by acute problems or anxiety. For example, a patient may feel very ambivalent about taking a new anti-inflammatory agent for pain because there is a substantial possibility of significant side effects. How-
ever, this ambivalence may change when the patient suddenly experiences an acute episode of severe pain.

Finally, it needs to be clarified how shared decision making can be implemented within the current health care system. Payers, sometimes indirectly, severely restrict the amount of time a physician has available to care for a patient. SDPs are good examples of how part of the process of shared decision making can occur in the absence of the physician. Most current health plans place limitations on the options that patients have available. Patients may also choose treatments that health plans consider too costly. Whether preference for more costly treatments for some patients would be offset by less use of other costly procedures remains to be seen.

In sum, the rationale for shared decision making is compelling. Most medical problems can be treated in multiple different ways. Each treatment option offers different trade-offs in quality of life and mortality, and there is often no objective "best" treatment. Rather, a treatment choice should be made based on an individual's preferences and willingness to accept risk.

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References


