In This Chapter

Finding the Evidence
- Search for Evidence on Infliximab for Rheumatoid Arthritis
- Search for Evidence on Associated Patient Decision Aids

Strategies for Incorporating Patient Values
- Implicit Values Elicitation
- Explicit Values Elicitation
- Levels of Patient Participation in Decision Making

Patient Decision Aids
- The Ottawa Decision Support Framework
- Advantages of Patient Decision Aids
- Do Patient Decision Aids Work?

Identification of Patient Values
- Balance Scales
- Formal Utility Assessments
- Threshold Techniques
- Analytic Hierarchy Process
You decide to conduct two searches, one on infliximab for treatment of rheumatoid arthritis and the second on associated decision aids.

**Search for Evidence on Infliximab for Rheumatoid Arthritis**

You frame the question as follows: Does the addition of infliximab to methotrexate decrease pain and swelling in patients with rheumatoid arthritis compared with methotrexate alone? To search for studies that address this question, you decide to use a hierarchy that you learned at a recent workshop provided by the hospital librarian. The hierarchy, which progresses from the most to the least evolved preprocessed evidence-based information sources, begins with *systems* as the highest level resource, followed by...
synopses of syntheses (systematic reviews), syntheses, synopses of single studies, and finally single studies (see Chapter 2, Finding the Evidence, for details about this hierarchy). Using this framework, you begin by searching Clinical Evidence, a systems-level, regularly updated, Web-based and print publication that integrates evidence-based information about specific clinical problems. You type in “infliximab,” which results in a few hits. You learn that infliximab is a tumor necrosis factor antagonist, the effectiveness of which is summarized in Clinical Evidence. The authors of this section found three placebo-controlled randomized trials, one of which included people with active disease not responsive to methotrexate. Although these authors do not mention a systematic review on the topic, you also check Evidence-Based Nursing for synopses of syntheses (systematic reviews) and the Cochrane Library for a synthesis. You type in the keyword “infliximab.” Although you get no hits in Evidence-Based Nursing, you do get one hit in the Cochrane Database of Systematic Reviews, entitled “Infliximab for the treatment of rheumatoid arthritis.”

The systematic review identifies the same randomized controlled trial that was summarized in Clinical Evidence, with results reported at 30 weeks and 54 weeks. In this trial, 428 patients who had active rheumatoid arthritis despite methotrexate therapy were randomized to methotrexate (same dose they had been receiving before the study) plus infusions of infliximab, 3 mg/kg every 4 weeks, or methotrexate plus placebo. Patients were unaware of whether they were receiving infliximab or placebo. An independent assessor, who had no knowledge of the patient’s treatment assignment, evaluated the number of tender and swollen joints in each group. Other outcomes included quality of life and effect on joint damage assessed radiographically. The investigators conducted an intention-to-treat analysis and, at 54 weeks, found that patients who received methotrexate plus infliximab had a sustained reduction in number of swollen joints (50% reduction with methotrexate plus infliximab vs. 13% with methotrexate alone; \( P < 0.001 \)) and number of tender joints (55% reduction vs. 23%; \( P < 0.001 \)) compared with patients who received methotrexate alone. Quality of life was also significantly better with methotrexate plus infliximab than with methotrexate alone. Radiographic evidence of joint damage increased in patients who received methotrexate alone, but not in those who received methotrexate plus infliximab (mean change in radiographic score, 7.0 vs. 0.6; \( P < 0.001 \)).

Despite these impressive findings about the clinical benefits of infliximab and its ability to halt the progression of joint damage, you appreciate the difficult decision the patient has to make. Although Clinical Evidence categorizes tumor necrosis factor antagonists such as infliximab as “likely to be beneficial” in the treatment of rheumatoid arthritis, it also states that short-term toxicity is relatively low, but the long-term safety is unclear. Common side effects include upper respiratory infections (cold), headache, diarrhea, and stomach pain. Other side effects, such as headache, nausea, and hives, can occur during or immediately after the injection of infliximab. Larger and longer-term studies of this drug are required because it has been associated with tuberculosis and other life-threatening infections.

**Search for Evidence on Associated Patient Decision Aids**

The rheumatology clinic has just purchased Evidence-based Rheumatology, a reference book available in both print and electronic (www.evidbasedrheum.com) form that reviews and updates the best evidence for treatments of rheumatologic disorders and
also provides decision aids. You click on the chapter on Decision Aids and then click on infliximab. You find a decision aid, “Should I take infliximab?”

The decision aid is based on evidence from the Cochrane systematic review described previously and can be used either by patients alone in preparation for discussions with their practitioner or by patients together with their practitioners. It guides patients to verify the decision, clarify their values about the benefits and harms of infliximab, determine their preferred role in decision making, identify remaining decisional needs, plan the next steps, and share their thinking with their practitioners.

Armed with the evidence and the decision aid, you prepare to meet with the patient. You are aware that the treatment decision will depend on the relative value the patient places on reduction of disability coupled with improved quality of life and prevention of progressive joint damage, compared with avoiding the risk of tuberculosis and other life-threatening infections. The patient’s values are crucial in making the decision.

**STRATEGIES FOR INCORPORATING PATIENT VALUES**

In other chapters of this book (Chapter 1, Introduction to Evidence-Based Nursing; Chapter 4, Health Care Interventions; Chapter 10, Moving from Evidence to Action Using Clinical Practice Guidelines; and Chapter 33, Applying Results to Individual Patients), we have proposed that clinical decision making should begin by using the best evidence to estimate the benefits, harms, and costs associated with alternative courses of action. We have pointed out that because interventions always have advantages and disadvantages, evidence alone cannot determine the best course of action. Most would agree that clinicians must use the values and preferences of the patient to balance harms and benefits. Not surprisingly, patients vary greatly in the value they place on different outcomes. Given this variability in patient’s values, clinicians should proceed with great care. It is easy to assume that a patient’s values are similar to one’s own, but this may be an incorrect assumption. The challenge, then, is to integrate the evidence with the patient’s values.

For many clinical decisions, the trade-off is sufficiently clear that clinicians do not need to be concerned about variability in patient values. Previously healthy patients will all want antibiotics to treat their pneumonia and anticoagulation to treat their pulmonary embolus; bedridden patients will want regular skin care and turning to prevent decubiti. Under such circumstances, a brief explanation of the rationale for treatment and the expected benefits and side effects will suffice. However, not all decisions are so straightforward. When benefits and risks are balanced more precariously and the best choice may differ across patients, clinicians must attend to the variability in patients’ values.

**Implicit Values Elicitation**

An *implicit* strategy for integrating evidence with preferences and values involves communicating the benefits and harms to patients, thus permitting them to incorporate their own values into the decision. The clinician typically shares the evidence, in some form, with the patient, while attempting to understand the patient’s values. One advantage of this approach is that it avoids the problem of measuring patients’ values. Unfortunately, communicating evidence about benefits and harms to patients in a way
that allows them to understand their choices and incorporate their preferences and values may be as difficult as directly measuring patient values.

**Explicit Values Elicitation**

An *explicit* strategy is to directly elicit patient values using formal measurement techniques, such as standard gambles or balance scales. These explicit approaches have the advantage of facilitating communication of values between patients and clinicians. Moreover, the more formal techniques provide values or utilities that can be incorporated into decision trees using decision analysis to determine which option has the highest expected value for the patient. The disadvantages of formal techniques include their complexity, impracticality in most practice settings, and potential for measurement errors.

**Levels of Patient Participation in Decision Making**

Patients often have preferences not only about the outcomes, but also about the decision-making process. These preferences can vary, and the patient's desired level of involvement should determine which approach the clinician takes. At one end of the spectrum, the clinician acts as a technician, providing the patient with information and taking no active part in the decision-making process. At the opposite extreme, the clinician ascertains the patient's values and then makes a recommendation in light of the likely advantages and disadvantages of alternative management approaches. In this paternalistic approach, the clinician decides what is best in light of the patient’s preferences.

Intermediate approaches of shared decision making are generally more popular than those at either extreme. Shared decision making uses both fundamental approaches to decision making: The clinician typically shares the evidence, in some form, with the patient, while attempting to understand the patient’s values. Evidence that more active patient involvement in the process of health care delivery can improve outcomes and reported quality of life—and possibly reduce health care expenditures—provides support for secular trends toward patient autonomy and movement away from paternalistic approaches.

**PATIENT DECISION AIDS**

To support patient decision making, researchers and clinicians have developed patient decision aids as adjuncts to counseling. *Decision aids* are shared decision-making programs that describe options in sufficient detail for patients to judge their value. They often include (1) information on the condition, options, benefits, and harms; (2) probabilities of benefits and harms, which may be tailored to a patient’s risk profile; (3) information about the level of scientific uncertainty regarding the probabilities of benefits and harms; (4) values clarification strategies to help patients consider the value or personal importance of benefits versus harms; (5) balanced stories of others’ experiences with decision making; and (6) guidance or coaching in the steps of decision making and communication, using strategies such as personal worksheets.
The Ottawa Decision Support Framework

Although the developers of decision aids have different conceptual frameworks of decision support, most are based on decision theories from economics and cognitive psychology that structure decisions according to options, outcomes, and probabilities of outcomes so that patients can better judge the value of the benefits versus the harms. Many frameworks broaden this cognitive perspective by including emotional, social, and environmental dimensions.

We developed the Ottawa Decision Support Framework, based on expectancy value, decisional conflict, and social support theories. The purpose of the framework is to guide clinicians in the process of decision support for health decisions that (1) are stimulated by a new circumstance, diagnosis, or developmental transition; (2) require careful deliberation because of the uncertain and/or value-sensitive nature of the benefits and harms; and (3) need relatively more effort during the deliberation phase than the implementation phase.

The framework (Table 34-1) includes three process elements: (1) assessment of needs or determinants of decisions that are suboptimal; (2) provision of decision support interventions that address the suboptimal determinants; and (3) evaluation of the effects of decision support on the quality of decision making and outcomes of decisions. The variables in the framework apply to both clinicians and patients, but discussion in this chapter is focused on the patient.

Determinants of Decisions

Essential inputs into decisions include the patients’ demographic, clinical, and practice characteristics, perceptions of the decision, perceptions of important others involved in the decision, and personal and external resources to make and implement a choice. The selection of one option over another depends not only on patient characteristics, but also on whether patients are knowledgeable about the issues, expect that the preferred option will likely lead to the outcomes they value most, are reasonably certain this is the best option, perceive that important others agree with and support the option, and have the necessary personal and external resources to make and implement the choice.

Decision Support

Decision support involves preparing patients for decision making and structuring follow-up counseling. The goal is to improve the quality of decision making by addressing the modifiable determinants of decisions that are suboptimal: inadequate knowledge, unrealistic expectations of outcome, unclear values, unclear norms, unwanted pressure, inadequate support, and inadequate personal and external resources to make the decision. These factors also contribute to decisional conflict. High decisional conflict or uncertainty results in poor decision quality, decision delay, regret, discontinuance, dissatisfaction, and overuse of health services that patients do not value.

Decision support includes providing tailored information, realigning outcome expectations, clarifying values, and augmenting skills in decision making and communication. Decision aids use these strategies in preparing patients for follow-up counseling. They include information about the problem, options, and benefits and harms to
### Table 34-1  Ottawa Decision Support Framework

<table>
<thead>
<tr>
<th>Characteristic</th>
<th>Provide Access to Information</th>
<th>Decision Making</th>
<th>Resources to Make Decision</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Assess Needs</strong> (Determinants of Decisions)</td>
<td></td>
<td></td>
<td><strong>Personal:</strong></td>
</tr>
<tr>
<td><strong>Client:</strong> Age, sex, marital status, education, occupation, culture, locale, medical diagnosis and duration, health status</td>
<td>• Health situation&lt;br&gt;• Options&lt;br&gt;• Outcomes&lt;br&gt;• Other’s opinions and choices</td>
<td>• Reduced decisional conflict&lt;br&gt;• Improved knowledge&lt;br&gt;• Realistic outcome expectations and norms&lt;br&gt;• Clear values&lt;br&gt;• Agreement between values and choice&lt;br&gt;• Implementation of chosen option&lt;br&gt;• Satisfaction with decision making</td>
<td>• Previous experience&lt;br&gt;• Self-confidence&lt;br&gt;• Motivation&lt;br&gt;• Skill in decision making</td>
</tr>
<tr>
<td><strong>Practitioner:</strong> Age, sex, education, specialty, culture, practice locale, experience, counseling style</td>
<td></td>
<td></td>
<td><strong>External:</strong></td>
</tr>
<tr>
<td><strong>Provide Decision Support</strong></td>
<td></td>
<td></td>
<td>• Support (information, advice, emotional, instrumental, financial, professional help) from social networks and agencies</td>
</tr>
<tr>
<td><strong>Evaluate Effects of Decision Support</strong></td>
<td></td>
<td></td>
<td><strong>Perceptions of Decision</strong></td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
<td>• Knowledge&lt;br&gt;• Expectations&lt;br&gt;• Values&lt;br&gt;• Decisional conflict&lt;br&gt;• Stage of decision making&lt;br&gt;• Predisposition toward options</td>
</tr>
<tr>
<td><strong>Perceptions of Others</strong></td>
<td></td>
<td></td>
<td><strong>Augment Skills by Providing Guidance/Coaching in:</strong>&lt;br&gt;• Steps in decision making&lt;br&gt;• Communicating with others&lt;br&gt;• Handling pressure&lt;br&gt;• Accessing support and resources</td>
</tr>
<tr>
<td>• Perceptions of others’ opinions and practices&lt;br&gt;• Support&lt;br&gt;• Pressures&lt;br&gt;• Roles in decision making</td>
<td><strong>Realign Expectations of Outcomes</strong>&lt;br&gt;<strong>Clarify Personal Values for Outcomes</strong></td>
<td></td>
<td><strong>Outcomes of Decision</strong></td>
</tr>
<tr>
<td><strong>Clarify Personal Values for Outcomes</strong>&lt;br&gt;<strong>Augment Skills by Providing Guidance/Coaching in:</strong>&lt;br&gt;• Steps in decision making</td>
<td></td>
<td></td>
<td>• Persistence with choice&lt;br&gt;• Improved values-linked quality of life&lt;br&gt;• Reduced distress&lt;br&gt;• Reduced regret&lt;br&gt;• Informed use of resources</td>
</tr>
<tr>
<td><strong>Evaluate Effects of Decision Support</strong></td>
<td></td>
<td></td>
<td><strong>Perceptions of Others</strong></td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
<td>• Perceptions of others’ opinions and practices&lt;br&gt;• Support&lt;br&gt;• Pressures&lt;br&gt;• Roles in decision making</td>
</tr>
</tbody>
</table>
improve knowledge of the decision. Probabilities tailored to a patient’s clinical risk are included to create more realistic expectations or subjective judgments of the likelihood of benefits and harms. Decision aids may also clarify personal values by either implicitly or explicitly asking individuals to consider the personal importance they place on each benefit and harm and to identify the trade-offs they will need to make in choosing one option. As a result, there is likely to be better congruence between patients’ values and their choices.

Evaluating Decision Support
The framework distinguishes between quality decision making and quality outcomes, because good decisions can still result in bad outcomes as a result of the probabilistic nature of clinical events. Because decisions that depend on patients’ values cannot be judged as right or wrong, the framework defines a high-quality decision as one that reduces decisional conflict, improves knowledge, incorporates realistic outcome expectations, is consistent with personal values, is enacted, and results in decision maker satisfaction. Improving decision making may impact favorably on behavioral, clinical, and health services outcomes of decisions, such as adherence to the chosen option, improved values-linked quality of life, reduced distress about the expected consequences of options, reduced regret, and appropriate use of resources.

Advantages of Patient Decision Aids
A well-constructed decision aid has two advantages over implicit values elicitation. One advantage is that someone has reviewed the literature and produced a rigorous summary of the probabilities. Clinicians who doubt the rigor of the summary of probabilities can go back to the original literature on which those probabilities are based and, using the principles of this book, determine their accuracy. A second advantage of a well-constructed decision aid is that it will offer a pretested and effective way of communicating the information to patients, who may have little background in quantitative decision making. Most commonly, decision aids use visual props to present outcome data in terms of the percentage of people with a certain condition who do well without an intervention compared with the percentage who do well with an intervention. Decision aids will summarize the data regarding all outcomes of importance to patients; however, many decision aids fail to address the scientific uncertainty about related benefits and harms.

Do Patient Decision Aids Work?
Theoretically, decision aids present an attractive strategy for ensuring that patient values guide clinical decision making. However, what impact do decision aids actually have on clinical practice? O’Connor and colleagues conducted a systematic review and identified 34 randomized trials that used 29 unique decision aids. In the trials comparing decision aids with usual care, the decision aid group had higher knowledge scores (weighted mean difference [WMD], 19 on a 100-point scale; 95% confidence interval [CI], 13 to 24), more realistic expectations (relative risk [RR], 1.4; 95% CI, 1.1 to 1.9), and lower decisional conflict related to feeling informed (WMD, –9.1; of 100; 95% CI, –12 to –6). A higher proportion of the decision aid group was active in decision making (RR, 1.4;
95% CI, 1.0 to 2.3), and a smaller proportion of this group remained undecided after the intervention (RR, 0.43; 95% CI, 0.3 to 0.7).

Decision aids with detailed information resulted in only marginally higher knowledge scores when compared with decision aids with briefer information (WMD, 4 out of 100; 95% CI, 3 to 6). Decision aids that included probabilities of outcomes produced more realistic expectations (perceived probabilities of benefits and harms) than decision aids without information on probabilities (RR, 1.5; 95% CI, 1.3 to 1.7), and those that included explicit values clarification exercises had greater agreement between values and choices than those that did not include these exercises.

Exposure to decision aids reduced rates of elective invasive surgery in favor of conservative options (RR, 0.77; 95% CI, 0.7 to 0.9), with variable effects on other decisions. Generally, decision aids were no better than comparators in affecting satisfaction with decision making or anxiety. Most trials showed no improvements in health outcomes. However, the health outcomes measured were not linked to personal values (e.g., did the decision aid increase the health outcomes patients valued most and decrease the outcomes patients valued least?).

As part of the systematic review to evaluate the impact of decision aids on patient decision making, O’Connor and colleagues also created a global inventory of existing patient decision aids and evaluated the quality of these aids using CREDIBLE criteria (C: competently developed; R: recently updated; E: evidence-based; DI: disclosure of conflicts of interest; BL: balanced presentation of options, benefits, and harms; and E: efficacious in improving decision making). The decision aids and more information about the CREDIBLE criteria can be found at http://decisionaid.ohri.ca/.

The medium for delivery of decision aids varies (e.g., print, boards, videos, audio-guided workbooks), and many developers are now producing Web-based applications. Nurses can provide coaching in the use of decision aids. One randomized trial focusing on treatment decisions for menorrhagia, compared usual care, a video decision aid, and a video decision aid with nurse coaching that included values clarification. The video plus nurse coaching was superior to the other interventions in terms of patient satisfaction and cost-effectiveness. Moreover, hysterectomy rates were significantly lower.

In summary, decision aids increase patient participation in decision making without affecting anxiety. They improve decision quality by increasing the chances that choices are based on better knowledge, more realistic outcome expectations, and personal values. They may have a role in preventing the overuse of aggressive surgical options that informed patients do not value, without adversely affecting health outcomes. Simple decision aids that clinicians can integrate into usual patient care could increase the extent to which patient values truly determine health care decisions.

IDENTIFICATION OF PATIENT VALUES

A key objective of decision aids is to help patients clarify and communicate the value they place on the outcomes associated with each option. Doing so requires that the patient understands the nature of those options and outcomes and improves the match
Incorporating Patient Values

Chapter 34

between what is personally most desirable and the option the patient chooses. There are several ways to help patients consider the value they attach to various options. The relative efficacy of different approaches is still under investigation.

Virtually all decision aids describe what it is like to undergo the related procedures and to live with the physical, emotional, and social consequences. Patients are better able to judge the value of consequences when the consequences are familiar, simple, and directly experienced.24

Some decision aids use social matching strategies. They begin by showing examples of how others value the features of an option to illustrate how different values may lead to different choices. Then they ask the patient to indicate which examples most closely match their own and which do not. This strategy may be more helpful for those who are not quantitatively oriented.

Some decision aids guide patients to compare, rate, or trade off different features of options using more quantitative methods. These engaging processes may increase awareness of personal values and provide insight into the trade-offs that need to be made in choosing one option over another. Some specific quantitative techniques for clarifying values in decision aids include balance scales, formal utility assessments, threshold techniques, and an analytic hierarchy process.

**Balance Scales**

In balance scale values clarification,15,34 standard features of an option are visually displayed on a “weighing scale” in which the benefits (pros) of an option are listed on the left and the harms (cons) on the right. Patients review the standard features and add others that are important in their situation. They then rate the desirability of each feature by shading or assigning stars (0 stars = not at all important to me; 5 stars = very important to me). Next, they make an overall value judgment using a “leaning scale” anchored by “Willing to consider treatment: pros are more important to me than the cons” and “Not willing to consider treatment: cons are more important to me than the pros,” with “unsure” situated in the middle. This technique is simple to administer, can be self-administered, and promotes communication of values at a glance. It has been used successfully in decision aids, and direct comparisons with more formal methods are under investigation.34

**Formal Utility Assessments**

Formal utility assessment techniques are based on expected utility theory and elicit the desirability of the outcomes of each option.21,35–37 These are more complex strategies and include the visual analog scale, standard gamble, and time trade-off. They are usually administered by a clinician or data collector rather than self-administered, although investigators have developed computer-based applications that may lend themselves to self-administration. Two randomized trials have successfully used the computer-based application.35,38

When using a visual analogue scale, the clinician asks the patient to place a mark on a 100-point scale or “feeling thermometer” (Figure 34-1). The mark signifies how the patient feels about the health state in question and can be placed anywhere between 0
Figure 34-1. Visual analogue scale as a “Feeling Thermometer.”
Incorporating Patient Values

Chapter 34

501

The value of the health state or outcome is the point where the patient places the mark. For example, if the patient places the mark on 90, the value of the health state is $90/100 = 0.90$. Because some health states, such as an infection, are temporary, whereas others, such as a stroke, are permanent, clinicians must ensure that patients incorporate the duration of the health state in their rating. Schünemann and colleagues validated a self-administered approach to the feeling thermometer.39

In the *standard gamble*, patients are asked to choose between living in a state of impaired health and taking a gamble in which they may return to full health or die immediately (see Chapter 12, Quality of Life). In a series of paired choices, patients indicate the probability at which they are indifferent between (1) the certainty of living the rest of their lives in an intermediate health state/outcome; or (2) a gamble in which there is a probability ($p$) of being restored to perfect health but a corresponding probability ($1 - p$) of immediate death. The utility for the health state/outcome is the probability ($p$) at which the patient is indifferent (e.g., 0.90 chance of perfect health).

In *time trade-off*, patients choose between a longer period in a state of impaired health (such as recovery from severe stroke) and a shorter period in a state of full health. Patients are given a series of paired choices through which they indicate the length of time in perfect health that is equivalent to a lifetime in an intermediate health state/outcome. The patient’s value for the outcome is calculated as the proportion that is indicated (e.g., $9/10$ years’ life expectancy $= 0.90$).

**Threshold Techniques**

The simplest form of threshold technique involves evaluating whether to choose option A or option B.40 Standard features of both options (their procedures, consequences, and chances) are visually displayed in parallel columns. After considering this information, patients indicate their initially preferred option. The relative strength of the preference for the initially preferred option is gauged by hypothetically altering the level of one of the features (e.g., probability of a positive or a negative outcome) in either the preferred or the rejected option, until the patient gives up the initially preferred option and switches to other option.

**Analytic Hierarchy Process**

The analytic hierarchy process begins with explicit definitions of the decision goal, the alternative options, and the criteria used to compare the options’ abilities to meet the goal.41 These elements are then organized into a hierarchical decision model, with the goal at the top, the alternatives at the bottom, and the criteria in the middle. The elements at each level are then compared relative to the element(s) at the next higher level to derive a ratio-level scale: for the criteria, the ratio-level scale indicates their importance relative to the decision goal; for the options, the ratio-level scale indicates how well they can be expected to meet the criteria. Finally, information about the relationships among the elements on each horizontal level of the hierarchy is combined.
Nurses who coach patients in preparation for shared decision making with their practitioners need to know the evidence about patients’ options and tailor their support to patients’ decisional needs. For example, they must address knowledge deficits by providing evidence-based information, resolve unclear values with values clarification exercises, help patients manage support deficits, and provide guidance in the steps of decision making. Evidence-based decision aids may streamline this process and help in follow-up discussions with the practitioner.

Furthermore, patients can carry over these basic skills in decision making to subsequent decisions in the chronic disease trajectory. For each choice, patients need to be involved in clearly articulating the decision, the timing of the decision, their role in decision making, their understanding of outcomes related to the options, and balancing the benefits and harms in relation to personal values. Evidence-based patient decision making continues to evolve, with an emphasis on identifying simple, effective ways to support patients in the process.
Decision Aid: Should I Take Infliximab?

This guide can help you make decisions about the treatment your doctor is asking you to consider.

It will help you to:
1. Clarify what you need to decide.
2. Consider the pros and cons of different choices.
3. Decide what role you want to have in choosing your treatment.
4. Identify what you need to help you make the decision.
5. Plan the next steps.
6. Share your thinking with your doctor.

Step 1. Clarify what you need to decide.

What is the decision?
Should I start taking infliximab when methotrexate alone is not working to control rheumatoid arthritis?

Infliximab is an intravenous (IV) injection given at set times every few weeks.

When does this decision have to be made? Check ✓ one
☐ within days
☑ within weeks
☐ within months

How far along are you with this decision? Check ✓ one
☐ I have not thought about it yet
☑ I am considering the choices
☐ I am close to making a choice
☐ I have already made a choice

Figure 34-2. Decision aid to assist patients in making treatment decisions. (Modified and reproduced with permission of BMJ Books from Tugwell P, Shea B, Boers M, et al., eds. Evidence-based Rheumatology. London: BMJ Publishing Group; 2003.)
Step 2. Consider the pros and cons of different choices.

What does the research show?

Infliximab is classified as: “Trade off between benefits and harms”

There is ‘gold’ level evidence from two studies of 428 people with rheumatoid arthritis. The studies tested infliximab and lasted 6 months to 1 year. (See chart for pros and cons.)

What do I think of the pros and cons of infliximab?

1. Review the common pros and cons.
2. Add any other pros and cons that are important to you.
3. Show how important each pro and con is to you by circling from one (•) star if it is a little important to you to up to five stars (*****) if it is very important to you.

<table>
<thead>
<tr>
<th>PROS (number of people affected)</th>
<th>How important is this to you?</th>
<th>CONS (number of people affected)</th>
<th>How important is this to you?</th>
</tr>
</thead>
<tbody>
<tr>
<td>Improves pain and function</td>
<td>★★★★★</td>
<td>Side effects: colds, headache, diarrhea, abdominal pain</td>
<td>★★★★</td>
</tr>
<tr>
<td></td>
<td></td>
<td>41 out of 100 people are helped at least a little</td>
<td>5 out of 100 people stopped taking infliximab because of the side effects</td>
</tr>
<tr>
<td></td>
<td></td>
<td>31 out of 100 are helped a lot</td>
<td>7 out of 100 people stopped taking methotrexate/placebo because of side effects</td>
</tr>
<tr>
<td>Slows progress of disease</td>
<td>★★★★</td>
<td>Reactions during or immediately after the injection</td>
<td>★★★★</td>
</tr>
<tr>
<td></td>
<td></td>
<td>X-rays are better in 47 out of 100 people</td>
<td>Headache, nausea, and hives</td>
</tr>
<tr>
<td>Works within weeks rather than months</td>
<td>★★★★</td>
<td>Serious harms: tuberculosis and other serious infections (some have caused death)</td>
<td>★★★★</td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Other pros:</td>
<td>★★★★★</td>
<td>Unsure if can travel with this medicine</td>
<td>★★★★★</td>
</tr>
<tr>
<td></td>
<td></td>
<td>Extra clinic visits and blood tests needed</td>
<td>★★★★★</td>
</tr>
<tr>
<td></td>
<td></td>
<td>Cost of medicine My drug plan covers this</td>
<td>★★★★</td>
</tr>
<tr>
<td></td>
<td></td>
<td>Other cons: Unknown long term effects</td>
<td>★★★★</td>
</tr>
</tbody>
</table>

What do you think about taking infliximab? Check one

- Willing to consider this treatment Pros are more important to me than the Cons
- Unsure
- Not willing to consider this treatment Cons are more important to me than the Pros

Figure 34-2—cont’d.
Step 3. Decide the role you want to have in choosing your treatment. Check one

- [ ] I prefer to decide on my own after listening to the opinions of others
- [✓] I prefer to share the decision with: my rheumatologist
- [ ] I prefer someone else to decide for me, namely:

Step 4. Identify what you need to help you make the decision.

Please circle your answers to these questions.

<table>
<thead>
<tr>
<th>What I know</th>
<th>Do you know enough about your condition to make a choice?</th>
<th>Yes</th>
<th>No</th>
<th>Unsure</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>Do you know which options are available to you?</td>
<td>Yes</td>
<td>No</td>
<td>Unsure</td>
</tr>
<tr>
<td></td>
<td>Do you know the good points (pros) of each option?</td>
<td>Yes</td>
<td>No</td>
<td>Unsure</td>
</tr>
<tr>
<td></td>
<td>Do you know the bad points (cons) of each option?</td>
<td>Yes</td>
<td>No</td>
<td>Unsure</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>What's important</th>
<th>Are you clear about which pros are most important to you?</th>
<th>Yes</th>
<th>No</th>
<th>Unsure</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>Are you clear about which cons are most important to you?</td>
<td>Yes</td>
<td>No</td>
<td>Unsure</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>How others help</th>
<th>Do you have enough support from others to make a choice?</th>
<th>Yes</th>
<th>No</th>
<th>Unsure</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>Are you choosing without pressure from others?</td>
<td>Yes</td>
<td>No</td>
<td>Unsure</td>
</tr>
<tr>
<td></td>
<td>Do you have enough advice to make a choice?</td>
<td>Yes</td>
<td>No</td>
<td>Unsure</td>
</tr>
</tbody>
</table>

| How sure I feel | Are you clear about the best choice for you?             | Yes | No | Unsure |
|                 | Do you feel sure about what to choose?                   | Yes | No | Unsure |

Decisional Conflict Scale © A. O'Connor 1993, Revised 1999

If you answered No or Unsure to many of these questions, you should talk to your doctor.

Step 5. Plan the next steps.

What do you need to do before you make this decision?

For example, I need to discuss the treatment plan with my rheumatologist

Step 6. Share the information on this form with your doctor.

It will help your doctor understand what you think about this treatment.

Figure 34-2.—cont’d.
REFERENCES


