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The Ottawa Patient Decision Aids

CONTEXT. Shared decision-making programs, or patient decision aids, have been developed for difficult decisions in which patients need to consider benefits versus risks.

PRACTICE PATTERN EXAMINED. Decision aids currently used in practice in Ottawa, Ontario, Canada.

DATA SOURCES. Published studies of patients faced with decisions about hormone therapy, prenatal testing, lung cancer treatments, and anticoagulation for atrial fibrillation; administrative data on distribution of decision aids; and a survey mailed to pulmonologists and surgeons.

RESULTS. Although most patients considering health care options arrive for counseling with strong predispositions toward a particular option, some are uncertain about their choice and express the need for information, clarification of values, and advice about their options. Decision aids prepare patients for decision making by increasing their knowledge about expected outcomes and personal values. The aids are used in our local centers, and more than 6000 kits have been distributed in Canada, the United States, Europe, and Australia. They primarily affect the decisions of patients who are undecided at baseline and sometimes reduce the proportion of patients who choose more intensive options.

CONCLUSION. The Ottawa patient decision aids assist patient decision making, particularly among those who are undecided.

Many health care decisions are difficult because the treatment outcomes are uncertain or the benefits need to be weighed against the risks.¹ Practice guidelines for such decisions often recommend that clinicians exercise judgment in applying the guidelines to individual patients and that patients' values concerning the outcomes be considered. For example, the American College of Physicians guidelines on preventive hormone replacement therapy (HRT) after menopause recommend that women understand the probable risks and benefits, decide how valuable they consider each potential effect, and participate with their physicians in deciding whether to receive HRT.² Applying these guidelines in practice is daunting, given the complexity of the decisions and the number of patients who will require counseling.

Several centers are now developing "decision aids" or "shared decision-making programs" as adjuncts to counseling.³⁻¹⁷ They provide information on options and outcomes relevant to a patient's disease or risk profile. Decision aids may be administered by using various media, such as decision boards, interactive videodiscs, personal computers, audio-guided workbooks, pamphlets, or group presentations.

We describe the decision aids that we have developed for use in our centers to prepare patients for counseling about complex, value-sensitive decisions. We use our framework to summarize the decision-making needs of our patients, our approach to decision support, and the results of our evaluation. We conclude with information about the use of these tools in practice.

The abstract of this paper is available at ecp.acponline.org.

The Ottawa Decision Support Framework

Most frameworks for patient decision making^{7, 18–23} are based on decision theories from economics and cognitive psychology.^{24–26} They structure decisions according to options, outcomes, and probabilities of outcomes so that patients are better able to judge the value of the benefits versus the risks. Several frameworks, including ours, have broadened this cognitive, rational perspective to include emotional, social, or environmental dimensions.^{27–32} The Ottawa Decision Support Framework⁷ uses the following three steps.

Step 1: Identify Needs

Baseline assessments help us to identify factors that affect choices and are suboptimal for decision making. For example, patients make suboptimal decisions if they

lack knowledge about options, have unrealistic expectations of outcomes, or are unclear about their own personal values. **Table 1** shows some of the baseline perceptions of patients deciding about HRT, prenatal testing, and chemotherapy.

We found that most patients are already predisposed toward a particular option. Others have also observed that 70% to 82% of patients come to counseling with a stated predisposition toward one option.^{14, 33–35} Although most of our patients leaned toward a particular option, others felt uncertain about what to choose. Moreover, most patients expressed problems with decision making, such as lack of information about options and outcomes, unclear personal values, and lack of advice. Patients' feelings of being uninformed were corroborated by their scores on tests that elicited knowledge of options and expectations (perceived probabilities) of

TABLE 1
Baseline Perceptions of Participants in the Ottawa Decision Aid Studies

VARIABLE	HORMONE REPLACEMENT THERAPY ⁷	PRENATAL TESTING ¹⁵	LUNG CANCER CHEMOTHERAPY [†]
Study population			
Description	94 women 50–60 years of age	21 pregnant women ≥ 35 years of age and their partners	20 patients with stage IV non-small-cell lung cancer who had just received counseling from an oncologist
Completed high school	80%	94%	75%
Perceptions of decision			
Does not lean strongly toward any one option	30%	29%	30%
Feels uncertain about choice*	57%	67%	55%
Feels uninformed about options, benefits, and risks*	43%	76%	25%
Lacks essential knowledge	46%	40%	28%
Has unrealistic perceptions of probabilities for outcomes	68%	63%	65%
Feels unclear about personal values*	68%	54%	28%
Perceptions of others			
Feels that advice is inadequate to assist in decision making*	87%	67%	30%
Feels unsupported in decision making*	52%	28%	5%
Feels pressure from others*	17%	28%	5%

*From a decisional conflict scale.³⁴

†Fiset V. Evaluating the effectiveness of a decision aid for patients considering treatment options for stage 4 non-small-cell lung cancer. Unpublished master's thesis.

outcomes. These findings are remarkable considering that half of the patients deciding about future use of HRT were already receiving it, all the patients with lung cancer had just received introductory counseling on treatment options from their oncologists, and participants in all three groups were well educated.

Step 2: Provide Decision Support

As shown in **Figure 1**, our approach to decision support involves preparing patients by using self-administered or group-administered decision aids, preparing practitioners by using scientific information or guidelines (or both), and structuring follow-up counseling.

Prepare the Patient

To prepare patients for decision making, decision aids are usually delivered by a self-administered, audio-guided workbook. Audiotapes (20 to 45 minutes) guide patients to review general information on the options (What are the options, benefits, and risks?) and to complete a personal worksheet (How does this information apply to me?).

General Information. First, patients learn about their condition, options, and outcomes. For example, through the HRT decision aid, women learn about major estrogen-related diseases after 50 years of age (osteoporosis, coro-

nary heart disease, endometrial cancer, and breast cancer), including their definitions, incidence, median age of onset, mortality rates, and functional impact; major risk factors for these diseases; disease prevention and early detection strategies; HRT regimens and their benefits and risks; and probabilities of outcomes (hip fracture, coronary heart disease, and breast cancer) with and without HRT. Probabilities are presented for women with and without these risk factors. The presentation of probabilities is numerical (e.g., 10 out of 100) and is accompanied by figures of 100 faces, shaded to illustrate the proportion of affected versus unaffected women. Estimates of the probabilities of outcomes are based on systematic overviews and modeling over a defined time horizon.

Personal Worksheet. Next, patients are guided by the audiotape to complete a worksheet on the personal issues related to the choice. The HRT decision aid guides women to identify their personal reasons for receiving or not receiving HRT (including assessment of personal risks for diseases affected by estrogen); clarify their values by using a “weigh scale” to rate their perception of the importance of the benefits and risks; identify their current health practices in promoting healthy bones, heart, and breasts; list their questions; identify their preferences for participation in decision making; and indicate their predisposition or “leaning” toward receiving HRT.

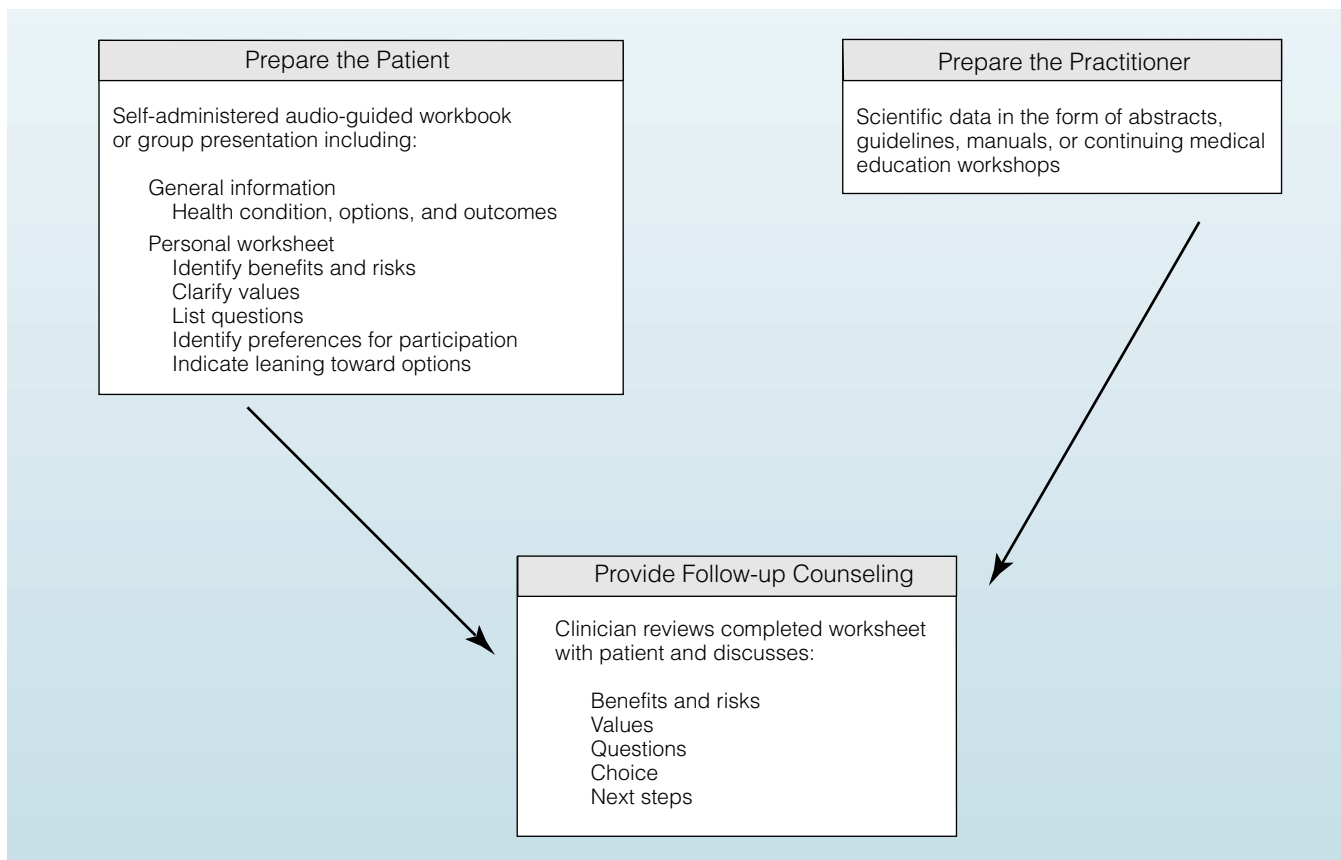


FIGURE 1. The Ottawa approach to providing decision support.

Before completing their own worksheet, participants are given examples of how different patients deliberate about options. The examples are composites of cases in our clinics. The decision aid presents a situation in which a patient chooses each of the options, including no treatment or testing. Patients learn not only what others choose but also the reasoning behind the choices. The different cases reinforce the notion that decision making is variable and should be individualized according to a person's own situation and values.

The worksheet helps patients process the objective information on options and outcomes in a form that they can use for decision making. People need to "personalize" the information by considering how it applies in their own situation. The worksheet can also be used to communicate their perceptions to others involved in the decision (e.g., a spouse or clinician).

Prepare the Practitioner

Practitioners prepare to use the decision aids by reading an accompanying manual or practice guideline that summarizes the scientific information on the decision. The practice guidelines were developed by a provincial or national group (e.g., Cancer Care Ontario or Society of Obstetrics and Gynecology). We have also held or contributed to local and national continuing medical education workshops that summarize the evidence about the options and efficacy of the decision aid in preparing patients for decision making.

Provide Follow-up Counseling

The patient's completed personal worksheet provides a focus for a follow-up discussion with his or her practitioner. At a glance, practitioners can learn how their patient has personalized the information on choices and what issues are relevant to him or her. They can then review the patient's perceived benefits and risks (given his or her risk factors), acknowledge the patient's values as revealed by the "weigh scale," answer questions, and facilitate decision making by considering the patient's preference for decision participation and predisposition toward options. Knowing a patient's preference for participation and whether he or she is predisposed toward a particular option can assist practitioners in judging how quickly they can move from facilitating decision making to follow-up planning.

Step 3: Evaluate Decision Support

Our evaluations of decision aids distinguish between improved decision making and improved outcomes. Decisions that depend on the patient's values cannot be judged as right or wrong—good decisions can still result

in bad outcomes as a result of the variable nature of clinical outcomes. Therefore, we define a good decision as one that is informed, consistent with personal values, and acted on and in which participants express satisfaction with decision making. **Table 2** outlines some of the results of our evaluations using before-and-after or randomized, controlled trial designs.

Do Decision Aids Address the Patient's Decision-Making Needs?

Yes. Decision aids reduce uncertainty about what to choose, improve knowledge, create realistic expectations, clarify personal values, and make patients feel supported in decision making.

Do Decision Aids Work Better Than Other Methods?

Probably. The decision aids were superior to a pamphlet or usual care in creating realistic expectations of benefits and risks and in making patients feel more informed. The HRT decision aid did not improve test scores when compared with a pamphlet, but it did help women to clarify personal values and feel supported in decision making. With the anticoagulation decision aid, there was a trend toward improved clarity of values relative to usual care but no improvement in patients' perception of support.

Do Decision Aids Affect Choices?

Variably. Compared with baseline or usual care, they usually reduce the proportion of patients who are uncertain about what to choose. Patients who are uncertain at baseline are most consistently affected by decision aids. Persons with strong preferences are less likely to change their minds, but in those who do, decision aids usually reduce their preference for more intensive options. Other trials comparing decision aids with usual care show that most of the aids reduce, or show a trend toward reducing, preferences for more intensive options.³⁶

Limitations

We attempted to recruit consecutive patients into our studies so that representation was as broad as possible. However, the most willing participants were better educated, and only two of the studies (the HRT trial and the lung cancer study) included participants whose educational levels were similar to those found in the regional census. The generalizability of our results to less educated and less motivated persons is unknown. The observational study designs limited our ability to attribute all of the observed effects to the prenatal testing and chemotherapy decision aids. However, we are reasonably confident that they improved knowledge, expectations, and the feeling

TABLE 2

Evaluation Studies of the Ottawa Decision Aids*

VARIABLE	OBSERVATIONAL STUDIES			RANDOMIZED TRIALS	
	HORMONE REPLACEMENT THERAPY ⁷	PRENATAL TESTING ¹⁵	LUNG CANCER CHEMOTHERAPY [†]	HORMONE REPLACEMENT THERAPY ⁸ (AUDIO-GUIDED WORKBOOK VS. PAMPHLET)	ANTICOAGULATION FOR ATRIAL FIBRILLATION ¹³ (DECISION AID VS. USUAL CARE)
Study population	94 women 50–60 years of age	21 pregnant women ≥35 years of age and their partners	20 patients with stage IV non–small-lung cancer	165 never-users of HRT 50–69 years of age	287 patients in atrial fibrillation
Completed high school	80%	94%	75%	74%	90%
Perceptions of decision					
Improves knowledge test score	Yes	Yes	Yes	No	Yes
Improves realistic expectations of outcomes	Yes	Yes	Yes	Yes	Yes
Improves certainty about choice	Yes	Yes	Yes	No	Yes
Improves feelings of being informed	Yes	Yes	Yes	Yes	Yes
Improves feelings of being clear about values	Yes	Yes	Yes	Yes	No
Perceptions of others					
Improves feelings of being supported	Yes	Yes	Yes	Yes	No
Decision making					
Reduces percentage of uncertain patients	Yes (RR, 0.68) [‡]	No (RR, 1.0)	Yes (RR, 0.33) [‡]	No (RR, 0.96)	Yes (RR, 0.16) [‡]
Affects choice	No (RR, 1.1)	Yes (RR, 0.56) [§]	No (RR, 1.1)	No (RR, 1.1)	Yes (RR, 0.67) [§]

*“Yes” indicates differences that are statistically significant ($P < 0.05$); HRT = hormone replacement therapy; RR = relative rate.

[†]Fiset V. Evaluating the effectiveness of a decision aid for patients considering treatment options for stage IV non–small-cell lung cancer. Unpublished master’s thesis.

[‡]Patients receiving decision aids are less uncertain.

[§]Patients receiving decision aids chose a less-invasive option

of being informed because of the short interval between the intervention and the post-test measurement.

Use in Clinical Practice

Table 3 lists the decision aids developed by using our approach. The clinical decisions were chosen because clinicians or patients indicated that these decisions were diffi-

cult to make, because of either the uncertainty of evidence on outcomes or, more commonly, the need to consider patients’ personal views of the treatment benefits versus the risks, inconvenience, and side effects. Other criteria that we used in deciding which aids to develop included the volume of patients requiring counseling; the in-house expertise and commitment to developing and updating the aid; and the existence of linkage to evidence networks,

TABLE 3

Decision Aids That Use the Ottawa Framework*

CONDITION	OPTIONS	DECISION MAKER	REFERENCE
Completed evaluations			
Women after menopause	HRT; lifestyle changes	Self	7, 8
Lung cancer, stage IV	Adding chemotherapy to supportive care and palliative radiation	Self, family	†
Pregnancy in women ≥ 35 years of age	Amniocentesis; chorionic villus sampling; maternal serum screening; no testing	Self, couples	15
Breast cancer	Breast conserving surgery; mastectomy	Self	17
Nonvalvular atrial fibrillation	Aspirin; warfarin; no treatment	Self, family	13
Under evaluation			
Elective cardiac surgery	Allogenic vs. autologous blood transfusion	Self, family	
End-stage COPD	Palliative care vs. mechanical ventilation and intubation	Self, family	
Feeding problems in cognitively impaired persons	Feeding tube via PEG gastric tube	Substitute decision maker	
Women ≥ 50 years of age with high risk for breast cancer	Preventive chemotherapy; investigative therapies; lifestyle options	Self	
Cognitive impairment	Location of care (home vs. institution)	Family caregiver	
Under development			
Osteoporosis	HRT; bisphosphonates	Self	

*More information is available on the World Wide Web: www.lri.ca; telephone (toll free): 888-240-7002; or e-mail: krobertson@lri.ca. COPD = chronic obstructive pulmonary disease; HRT = hormone replacement therapy; PEG = percutaneous endoscopic gastrostomy.

†Fiset V. Evaluating the effectiveness of a decision aid for patients considering treatment options for stage 4 non-small-cell lung cancer. Unpublished master's thesis.

such as the Cochrane Collaboration and the Cancer Care Ontario Guideline Initiative. Further information about the aids is available on our Web site (www.lri.ca).

The decision aids have been made more accessible to less literate persons by use of illustrations, audio-guidance, and text at a grade-8 reading level or lower. We have found that most patients prefer that the information be simply presented. Even though better-educated patients may be able to deal with more complicated approaches, they do not usually have the time to do so. To facilitate dissemination, we have adapted the HRT aid so that it may be used on a computer (via CD-ROM or the Internet) or in groups. Group delivery involves having a clinician present the information in the decision aid on slides and guiding the group to complete the

personal worksheet. Discussion about the pros and cons of HRT usually ensues. Women may benefit from both hearing the views of others and personalizing the information for themselves.

The HRT kits are used locally in our family practices, menopause clinics, osteoporosis clinics, and breast health centers. The Institute for Clinical Evaluative Sciences in Ontario sponsored its initial development and distribution to all public libraries in Ontario and to several women's clinics and community centers. We have used the aid at numerous group education nights for patients on our waiting lists for the menopause clinics and at events across the province sponsored by cancer, gynecologic, and osteoporosis societies. More than 5000 HRT decision aids have been distributed on a cost-recov-

ery basis to practitioners and patients across Canada, 20 states, England, France, Israel, and Singapore. The centers that have ordered the kits include physicians' offices, occupational health departments in industry, HMOs, and community health centers.

The lung cancer kit has been distributed to all pulmonologists and lung surgeons in Ontario. Referrals for chemotherapy treatment from our region are low, and we plan to monitor any changes in referrals after distribution of the new Cancer Care Ontario Guidelines and the decision aid kits. We also sent a survey to Ontario pulmonologists and surgeons; 36% of 164 eligible participants responded. About half the respondents took the time to review the decision aid and to comment on it. Reviewers ($n = 29$) were more likely to see larger numbers of lung cancer patients and to be thoracic surgeons. Two thirds to three quarters of reviewers thought that the decision aid was accurate, balanced, and useful for helping patients to become informed, considered their personal values, and enabled them to participate in decision making according to their needs. Most reviewers agreed that the decision aid would be easy to use, be suitable for their patients, complement their usual approach, help patients make better decisions, and do more good than harm. About one third agreed that it would save them time or help streamline their counseling. Two thirds said they would be comfortable providing it to their patients. The lung cancer kit is also being distributed to practitioners in Australia.

The breast cancer surgery kit was developed by the Institute for Clinical Evaluative Sciences in Ontario using the Ottawa system. A simpler brochure that summarizes key information on options and outcomes is also available. The audio-guided workbook and brochures were distributed to 421 surgeons in Ontario, along with an order form for additional copies. In response to this mailing, 95 surgeons ordered workbooks and brochures. The Canadian Cancer Society Information Service is now the main distributor of the brochures and workbooks to cancer patients. Between May 1998 and January 1999, they distributed 1781 brochures and 605 kits to cancer patients, family members, family physicians, and surgeons.

Distribution of the anticoagulation decision aid is under review by the Canadian Heart and Stroke Foundation. The prenatal decision aid is currently being revised to accommodate the change in counseling delivery at our regional center. Patients will be screened by telephone and will have the self-administered decision aid sent to their homes in preparation for group counseling.

Conclusion

The Ottawa decision aids improve decision making by helping undecided patients make choices and by

increasing the likelihood that decisions are based on better knowledge, realistic expectations, and personal values. These results are consistent with other published evaluations of decision aids. The long-term effects on the consistency of the choice made and patient satisfaction must be established. Moreover, the most cost-effective strategies for implementing these tools in everyday practice remain to be identified.

Take-Home Points

- Many patients facing medical decisions feel uninformed and uncertain about which option to choose.
- The Ottawa decision aids are a series of evidence-based, take-home, self-administered tools to prepare patients to make selected decisions.
- Patients like information to be presented simply; better-educated patients may be able to deal with more complicated approaches but do not usually have the time to do so.
- Although the Ottawa decision aids rarely change patients' predispositions, they help most patients become better informed and more aware of their own personal values; decision aids have their greatest impact among patients who are uncertain about which option to choose.
- Decision aids complement—but do not replace—counseling by practitioners.

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