Decision Making in Oncology: A Review of Patient Decision Aids to Support Patient Participation

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ABSTRACT Although cancer management is becoming more structured with disease-specific guidelines and clinical pathways, many decisions remain complex. Contributing to this complexity is the need to make value tradeoffs between benefits and harms across cancer treatment and/or screening options. Since there is no “best” option for everyone, decisions are defined as being of higher quality when informed with the latest scientific evidence and based on patients’ informed values associated with outcomes of options. However, clinicians are not good judges of patients’ values, and patients often have inadequate knowledge, unrealistic expectations, and decisional conflict that interfere with their involvement in decision making. Effective approaches to support patient involvement into clinical decisions include clinicians trained in shared decision making, question prompt sheets, patient decision aids, and decision coaching by nurses and other allied health professionals. Based on systematic review of 23 randomized trials of cancer patient decision aids, patients exposed to decision aids are more likely to participate in decision making and achieve higher-quality decisions. This review highlights key historical changes leading to patient involvement in decision making, summarizes evidence on effective interventions to support shared decision making, explores strategies to implement these interventions in oncology practices, and identifies future directions. (CA Cancer J Clin 2008;58:293–304.) © American Cancer Society, Inc., 2008.

INTRODUCTION

Over the last 3 decades, cancer treatments have become increasingly more sophisticated as a result of research and technological advances. Some clinical decisions are straightforward, with clear evidence to support one best approach, while other decisions are more difficult because of their preference-sensitive nature. Preference-sensitive decisions require weighing of patients’ values for benefits and harms across options, including the option of doing nothing (see Table 1).1 At the same time, there has been a rapid expansion in medical information, improved access to health information for patients, and an evolution in the patient’s role in decision making. A growing percentage of patients has shifted from being passive bystanders to active participants in the clinical decision-making process. Yet many patients feel uncertain about the best course of action and require support to participate in the decision-making process.2

The goal for preference-sensitive decisions where there is no “best” choice for everyone is to achieve a higher-quality decision. Decision quality is defined as the degree to which decisions are based on current scientific evidence and consistent with patients’ informed values and preferences.3–5 However, emerging evidence suggests that decision quality resulting from standard counseling in clinical practice is inadequate.6–9 In these studies of standard counseling, physicians focus on information-giving only without consideration of patients’ expectations or values associated with outcomes of options. As a result, patients exposed to current practice do not necessarily receive cancer treatment or screening tests that they value.10 Patient involvement in the decision-making process can help to improve
satisfaction, understanding, and confidence in
the decisions that are made.11 Furthermore, sup-
porting patients to be involved in decision mak-
ing is recognized as an important facet of
patient-centered care.12,13

The purpose of this review is to highlight key
historical changes leading to patient involve-
ment in decision making, summarize evidence
on approaches and effective interventions to sup-
port shared decision making, explore strategies
to implement these interventions in oncology
practices, and identify future directions.

HISTORICAL PERSPECTIVES

There has been a major shift in the approaches
to clinical decision making within the last gen-
eration of practicing physicians. For much of
the 20th century, physicians and their designates
were considered the keepers of medical infor-
mation and the sole decision makers. This is
referred to as the so-called “paternalistic model.”14
For this approach to decision making, physicians
and other health care professionals were expected
to make decisions on behalf of their patients,
often with little or no input from the patients
themselves or their families. The physicians’ per-
spective took precedence, and they had the bur-
den of responsibility for making vital decisions
for patients.

Since the 1970s, there has been increasing
recognition that patients need to be better
informed about their medical care, and informed
consent was introduced. Currently, cancer patients
routinely provide written consent for surgery,
radiotherapy, chemotherapy, and genetic testing.
Although informed consent as described in leg-
islation generally implies that patients are informed
of a particular treatment in light of alternative
options, consent forms primarily focus on the
potential benefits and side effects of the chosen
treatment.15–18 Furthermore, the process of obtain-
ing informed consent does not necessarily indi-
cate that patients are involved in making their
cancer decision; rather, the signature indicates
that they agreed to the treatment, which may
have been a recommendation by their physician.

Surveys of patients across different health con-
tions consistently indicate that the majority
want and expect to be involved in making health
decisions.19–22 These patients see themselves as
being responsible for their health and well-being,
which includes wanting to be fully involved in
decision making when they become ill. Perhaps
more importantly, evidence is beginning to emerge
to indicate that women with breast cancer who
have been actively involved in deciding about
their treatment tend to be more satisfied with the
care they receive, as well as having higher overall
quality of life, higher physical and social func-
tioning, and fewer reported side effects.23,24

Concurrently, within health professionals’ organ-
izations, there is increased emphasis on client-
centered care that includes expectations that
patients are involved in making health decisions.12,13

An important milestone for the promotion
of active patient participation as a routine part of
health care occurred in 2007; Washington state
passed the first informed-consent legislation to
indicate the need to acknowledge that shared
decision making occurred as evidence to sup-
port informed consent to treatment.25 The
description of shared decision making within
this legislation includes patient engagement in
decision making, use of patient decision aids,
and the need to ensure patients’ understanding
of the seriousness of the disease and available
treatment alternatives (eg, risks, benefits, and
uncertainties). State legislators and advocates of
patient involvement in shared decision making
are monitoring the implementation of this inno-
vative legislation.

APPROACHES TO PATIENT INVOLVEMENT
IN DECISION MAKING

Given the shortcomings of the paternalistic
approach to patient decision making, some
patient advocacy groups strongly promote a
“consumer model” in which the health care
team diagnoses the problem, provides the options,
and subsequently allows the patient to make the
decision in a fairly autonomous manner.14 This
consumer approach also has limitations. Allowing
patients and their families to deliberate on and
make decisions independently can lead to sig-
nificant patient uncertainty about the best course
of action, and clinicians may not be comfort-
able following through with the patient’s chosen
option (eg, use of unproven herbal therapies).

Although a small proportion of patients prefers
either a completely passive or completely active
decision-making role, within the last decade,
the prevailing approach for patient involvement
in decision making among the majority has been
“shared decision making.”22,23,25–29 Shared deci-
sion making is a process whereby patients
together with their clinician discuss the current
evidence on options and arrive at a mutually
agreed-on choice.14,30,31 Elwyn and colleagues
expanded the definition to include practition-
ers making explicit the uncertainty or equipoise
surrounding the decision.31 Therefore, shared
decision making facilitates an individualized
patient-centered approach in which patients
actively participate in achieving quality deci-
sions that are based on their informed values.
Through this process, patients’ views are clearly
acknowledged and valued by the health care
team (see Table 2).

At present, shared decision making is not
widely prevalent in clinical practice, and many
clinicians have yet to fully embrace this
approach.32 Specifically with regard to cancer
care, recently published studies suggest that
oncologists often do not involve patients in the
decision-making process to the extent that is
desired.33–35 Furthermore, clinicians often under-
estimate their patients’ preferences to be involved
in clinical decisions.7,8 Therefore, it is essential
to explicitly discuss with patients the role they
prefer in the decision-making process. Patient
preferences are difficult to predict and are not cor-
related with age, gender, educational status, or
income, so an individualized approach is re-
quired.26,27 For example, a study in which a hypo-
thetical case scenario of early-stage prostate
cancer was presented to clinicians found that
urologists usually recommend removing the can-
cer surgically, while radiation oncologists tend
to recommend radiotherapy.36 These early-stage
prostate cancer patients rarely receive guidance
from these specialists in making the best deci-
sion for their individual circumstances.

There are several known barriers to using
shared decision making in clinical practice. In a
review of 28 studies, the most common barriers
were health care professionals’ concerns about
not having enough time, perception that patient
characteristics or clinical situations were not con-
ducive to shared decision making, view that some
patients prefer a paternalistic approach without
asking patients about their preferred role in deci-
sion making, and limited familiarity with shared
decision making.32 Alternatively, some clinicians
were very motivated to engage patients in shared
decision making and believed that it would lead
to a positive impact on the clinician-patient
encounter and clinical outcomes. These clini-
cians also agreed that shared decision making
was useful and that most patients want to par-
ticipate in making decisions together with their
clinicians. Interventions such as educational train-
ing workshops on shared decision making and
tools to screen for decisional conflict in routine
clinical practice may overcome some of the
known barriers.32

**THE PROBLEM—DECISIONAL CONFLICT**

Patients faced with different options for can-
cer screening and/or treatment are likely to expe-
rience decisional conflict. Decisional conflict
occurs when individuals experience “uncertainty
about which course of action to take when choice
among competing options involves risk, loss,
regret, or challenge to personal life values.”37
Unfortunately, those experiencing decisional
conflict are more likely to change their minds,
delay making a decision, regret the decision(s)
they have made, fail a knowledge test, and blame
their doctors for bad outcomes.38–40 An obvious

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**TABLE 2** Reasons for a Shared Decision-making Approach

| Reason for Shared Decision-making Approach | |
|--------------------------------------------|--|
| Provide patient-centered care               | |
| Comply with legal and ethical patient rights| |
| Be responsive to patients’ desire to be involved| |
| Remain accountable for screening and treatments used| |
| Improve patient satisfaction with the decision-making process | |
| Potentially improve patient health outcomes | |
indication of decisional conflict is verbalized uncertainty, but other, more subtle signs include being preoccupied with the decision, being concerned about potential “bad” outcomes, and feeling distressed or tense.

A substantial proportion of individuals making preference-sensitive cancer-related decisions experience decisional conflict. For example, 66% of women with early-stage breast cancer reported feeling uncertain about whether to choose mastectomy or lumpectomy with radiation therapy.41 Another study indicated that 43% of patients with advanced cancer were uncertain about whether to receive end-of-life care at home or in a health care institution.42 In a third study of cancer patients with advanced non-small–cell lung cancer, only 30% felt sure about choosing chemotherapy or best supportive therapy.43 Key factors contributing to patients’ decisional conflict across these studies included feeling uninformed, unclear about their values, and unsupported in decision making.

INTERVENTIONS TO FACILITATE PATIENTS’ PARTICIPATION

Patients require targeted approaches to prepare them for participating in the medical consultation, sharing in the decision-making process, and overcoming factors contributing to decisional conflict. Ideally, interventions should help patients recognize that a decision needs to be made, understand the current scientific evidence, clarify their values associated with outcomes of options, and achieve a quality decision.3 While usual patient education materials are not adequate, question prompt sheets and consultation planning are effective interventions to facilitate cancer patient involvement in the medical consultation,44 and both patient decision aids and decision coaching facilitate patients’ roles in shared decision making and help them achieve higher-quality decisions.10

Question prompt sheets are standardized sets of questions used by patients to acquire information during the consultation.45 Studies indicate that patients who used question prompt sheets asked more questions, and their information needs were more likely to be met, but they had no difference in anxiety or satisfaction when compared with patients in the control group.44-46 Consultation planning is a process whereby patients are coached by trained facilitators (typically nurses, patient navigators, or resource center staff) to make their own lists of questions to ask within the medical visit.47 Breast cancer patients who participated in consultation planning were more satisfied and reported fewer barriers to communicating with their oncologist.48,49 However, further research is required to address what effect these interventions have on improving discussion of patients’ informed values associated with their options, an important element of decision quality.

Patient decision aids are tools that translate evidence into a patient-friendly form by providing, at a minimum, information on the options, benefits and risks, and implicit methods to clarify personal values.50 In addition, many decision aids also include information on the condition, probabilities of the outcomes of options (benefits/harms), exercises to help patients explicitly clarify their values, and guidance in the steps of decision making (see Table 3). Most patient decision aids are self-administered and are available in a variety of formats (paper-based resources, videos/DVDs, or computer software). However, there are some practitioner-administered decision aids, and these can involve more complex approaches.53,60,61 In recent years, the Internet has become the most widely available resource for patient decision aids, given the ease of updating the tools as new evidence emerges and the minimal costs associated with dissemination.

A recent update of the Cochrane review of patient decision aids identified 55 randomized controlled trials. Of these, 23 were focused on cancer-related decisions such as prostate cancer screening (n = 8), colon cancer screening (n = 3), breast cancer genetic testing (n = 6), breast cancer treatment (n = 4), and prostate cancer treatment (n = 2) (see Table 3). Patient decision aids, in general, were found to consistently improve knowledge, reduce decisional conflict, and result in choices that were congruent with patients’ values.10 When cancer-specific decision aids were compared with usual care, people receiving patient decision aids had higher average knowledge scores (weighted mean difference
| Source, Year, Location | Options Considered | Comparison of Most and Least Intensive Intervention | Elements in Decision Aids |
|-----------------------|-------------------|--------------------------------------------------|---------------------------|
| **Source, Year, Location** | **Options Considered** | **Comparison of Most and Least Intensive Intervention** | **Elements in Decision Aids** |
| | | | Options and Outcomes | Clinical Problem | Outcome Probability | Explicit Value | Clarification | Guidance in Steps of Decision Making | Decision Making |
| Goel V, Sawka CA, Thiel EC, et al, 2001, Canada | Breast cancer surgery | Audiotape and booklet PtDA (n = 86) | X | X | X | X | X |
| | | Simple PtDA pamphlet (n = 50) | X | X | — | — | — |
| Street RL Jr, Voigt B, Geyer C Jr, et al, 1995, United States | Breast cancer surgery | Interactive multimedia PtDA (n = 30) | X | X | — | — | X |
| | | Simple PtDA (n = 30) | X | X | — | — | — |
| Whelan T, Levine M, Willan A, et al, 2004, Canada | Breast cancer surgery | Decision board PtDA (n = 94) | X | — | X | — | — |
| | | Usual care (n = 107) | — | — | — | — | — |
| Green MJ, Biesecker BB, McInerney AM, et al, 2001, United States | Breast cancer genetic testing for higher-risk women | CD-Rom PtDA plus counseling (n = 29) | X | X | — | — | — |
| | | Usual care (n = 14) | — | — | — | — | — |
| Lerman C, Biesecker B, Benkendorf JL, et al, 1997, United States | Breast cancer genetic testing | Discussion PtDA and counseling (n = 122) | X | X | X | X | — |
| | | Usual care, wait-list control (n = 164) | — | — | — | — | — |
| Miller SM, Fleisher L, Roussi P, et al, 2005, United States | Breast cancer genetic testing (n = 279) | Discussion PtDA and general information pamphlets | X | X | — | — | — |
| | | General information pamphlets | X | X | — | — | — |
| Schwartz MD, Benkendorf L, Jerman C, et al, 2001, United States | Breast cancer genetic testing for Ashkenazi Jewish women | Booklet PtDA (n = 191) | X | X | — | — | — |
| | | Usual care (n = 190) | — | X | — | — | — |
| van Roosmalen MS, Stalmeier PF, Verhof LC, et al, 2004, The Netherlands | Prophylactic surgery for women with BRCA1/2 mutation | Video and brochure PtDA with decision analysis (n = 44) | X | X | X | X | — |
| | | Same video and brochure PtDA pamphlet (n = 44) | X | X | — | — | — |
| Whelan T, Sawka C, Levine M, et al, 2003, Canada | Breast cancer chemotherapy | Decision board PtDA and booklet (n = 82) | X | X | — | — | — |
| | | Usual care with booklet (n = 93) | — | X | — | — | — |
| Dolan JG, Frisina S, 2002, United States | Colon cancer screening in adults | Computer: analytic hierarchy process and pamphlet PtDA (n = 50) | X | X | X | X | — |
| | | Usual care (n = 47) | — | X | — | — | — |
| Pignone M, Harris R, Kinsinger L, 2000, United States | Colon cancer screening in adults | Video PtDA (n = 125) | X | X | — | — | — |
| | | Usual care (n = 124) | — | X | — | — | — |
| Wolf AM, Schorling JB, 2000, United States | Colon cancer screening in seniors | Script PtDA (n = 266) | X | X | — | — | — |
| | | Usual care (n = 133) | — | X | — | — | — |
| Auvinen A, Hakama M, Ala-Opas M, et al, 2004, Finland | Prostate cancer treatment | Pamphlet PtDA (n = 103) | X | — | X | — | — |
| | | Standard care clinical guideline (n = 100) | — | — | — | — | — |
| Davison BJ, Degner LF, 1997, Canada | Prostate cancer treatment | Written materials PtDA and audiotape of consultation (n = 30) | X | X | — | — | — |
| | | Usual care (n = 30) | — | X | — | — | — |
| Frosch DL, Kaplan RM, Felitti V, 2003, United States | PSA testing | Video PtDA (n = 112) | X | X | — | — | — |
| | | Internet presentation mirroring content of video (n = 114) | X | X | — | — | — |
| Gattellari M, Ward JE, 2003, Australia | PSA testing | Pamphlet PtDA (n = 126) | X | X | X | X | — |
| | | General information leaflet (n = 122) | — | — | — | — | — |
| Gattellari M, Ward JE, 2005, Australia | PSA testing | Pamphlet PtDA (n = 140) | X | X | X | X | — |
| | | General information leaflet (n = 140) | — | — | — | — | — |
| Myers RE, Daskalakis C, Cocroft J, et al, 2005, United States | PSA testing | Discussion PtDA and general information pamphlet (n = 121) | X | X | — | X | — |
| | | General information pamphlet (n = 121) | X | X | — | — | — |

— continued
[WMD] 13.7%, 95% confidence interval [CI] 9.0, 18.5); the 3 studies comparing detailed with simpler patient decision aids showed a smaller effect (WMD 4.1%, 95% CI 1.6, 6.5) (Figure 1). People receiving cancer-specific decision aids with descriptions of outcomes and probabilities were more likely to have accurate risk perceptions than those who did not receive this information; the pooled relative risk (RR) of having accurate risk perceptions was 1.5 (95% CI 1.2, 1.9) (Figure 2). Furthermore, there was a 50% reduction in the proportion of patients who assumed a passive (practitioner-controlled) role in decision making (pooled RR 0.5, 95% CI 0.4, 0.7) (Figure 3).

### TABLE 3 (continued)

| Source, Year, Location | Options Considered | Comparison of Most and Least Intensive Intervention | Elements in Decision Aids |
|------------------------|-------------------|---------------------------------------------------|--------------------------|
| Partin MR, Nelson D, Radosevich D. et al.70 2004, Canada | PSA testing Video PtDA (n = 384) | X X X X X | X X X X X |
| Schapira MM, VanRuiswyk J.71 2000, United States | Prostate cancer screening Booklet PtDA (n = 122) | X X X | — — — |
| Volk RJ, Cass AR, Spann SJ.72 1999, United States | Prostate cancer screening Video with pamphlet PtDA (n = 80) | X X X | — — — |
| Wolf AM, Nasser JF, Wolf AM, Schorling JB.73 1996, United States | Prostate cancer screening Script PtDA (n = 103) | X X X | — — — |

Abbreviations: PSA, prostate-specific antigen; PtDA, patient decision aid; X, present; —, absent.
CI 0.3, 0.8) (Figure 3). Overall, decision aids did not have adverse effects on anxiety, health status, or patient satisfaction.

Patient decision aids can potentially reduce overuse of some aggressive interventions (eg, orchiectomy for prostate cancer) and also reduce underuse of other interventions (eg, colon cancer screening), particularly when base rates are either very high or very low, respectively (see Figure 4). Patient decision aids have also been shown to reduce the use of aggressive interventions when base rates are already low. For example, women with early-stage breast cancer who utilized a decision aid were less likely to choose mastectomy compared with lumpectomy plus radiation despite seemingly low baseline rates of mastectomy (24% to 40%).52,53 For cancer screening, of 8 studies evaluating patient decision aids for prostate-specific antigen testing, 3 found significant reductions of 11% to 42% in men’s preference for screening,62,66,72 and the other studies found either nonsignificant increases67,69 or reductions68,70,71.

FIGURE 2  Effect of Patient Decision Aids for Cancer-related Decisions on the Proportion of Patients Classified as Having Accurate Risk Perceptions: Decision Aid with Outcome Probabilities Versus No Probability Information.

FIGURE 3  Effect of Patient Decision Aids for Cancer-related Decisions on the Proportion of Patients Reporting that Their Doctor Made the Decision.
in preference for screening. These results appear to highlight the controversy and uncertainty that currently exist regarding the overall value of prostate-specific antigen screening. Two studies that evaluated the effect of patient decision aids for colon cancer screening found no difference, and another study found a 64% uptake in colon cancer screening. There were no differences in preferences between groups for breast cancer genetic testing54–56,58 or breast cancer adjuvant chemotherapy.

Decision coaching is a process of facilitating patient engagement in shared decision making. Decision coaches are health professionals who (a) assess patients’ decisional conflict and related needs; (b) tailor decision support to address patients’ needs by offering patient decision aids and/or providing evidence-based information, verifying understanding, clarifying values, and building skills in accessing support; (c) guide patients through the decision-making process; and (d) monitor for factors that can influence implementing the decision (eg, motivation, self-efficacy, barriers). Studies of decision coaching indicate that when combined with patient decision aids, it improves decision quality, increases patient satisfaction, and is cost-effective. For example, the study by Wirrmann and colleagues on the effect of decision aids plus nurse coaching for men considering prostate cancer treatment found that men in the intervention group had higher knowledge.

FIGURE 4  Effect of Patient Decision Aids on Specific Cancer-related Treatment and Screening Decisions.
scores and were more likely to receive treatment congruent with their values.76

### STRATEGIES TO IMPLEMENT DECISION AIDS IN ONCOLOGY PRACTICE

Successful implementation of interventions such as patient decision aids in clinical practice requires access to the interventions, practitioners aware of and skilled in using them, and environmental structures that support their use.77 The Cochrane Inventory of Patient Decision Aids has over 500, with over 200 that are currently available.78 Some decision aids are produced by academic teaching institutions, while others are mass produced by health information organizations. For example, mass producers of decision aids including cancer-related topics are the Foundation for Informed Medical Decision Making (www.fimdm.org), Healthwise (www.healthwise.org), the Mayo Clinic (www.mayoclinic.org), and the Ottawa Health Research Institute (www.ohri.ca/decisionaid). The Ottawa Health Research Institute also has a personal decision guide that is an interactive tool useful for exploring any decision.

Given the variable quality of available patient decision aids, a group of experts from 14 countries established consensus on a set of criteria for judging their quality.3 These criteria are categorized into the domains of essential content, development process, and evaluation. The International Patient Decision Aid Standards (IPDAS) Collaboration’s criteria is available as a checklist (www.ipdas.ohri.ca) and is currently being used to quality-rate patient decision aids that are publicly accessible. These quality ratings are available at www.ohri.ca/decisionaid (see Decision Aid Library Inventory). The IPDAS checklist was designed to be used by developers, patients, health care professionals, health care insurers, administrators, policy makers, and researchers to critically appraise individual decision aids or to compare across available decision aids on the same topic.

Patients can access most available decision aids directly on the Internet or be given the decision aid or its URL by health care professionals or disease-specific community resource programs.79 For example, several cancer programs have integrated decision aids and decision-quality measures within the process of care for women with breast cancer considering treatment options.30,83 In primary care, cancer screening decision aids have also been incorporated into routine medical visits.82,83 Factors influencing successful implementation of decision aids in practice were reminders in the scheduling system, patient decision aids integrated with patient flow through the clinic, and physicians recommending them.52,80

### IMPLICATIONS FOR FUTURE RESEARCH AND PRACTICE

Gaps in knowledge remain. Further research is required to evaluate the influence of patient decision aids on patient-clinician communication; best practices for streamlining the updating process; and downstream effects, such as patient satisfaction and overall health outcomes, once they are more fully utilized.79 One study found that practitioners’ interactions with women who prepared for the consultation by using patient decision aids were more likely to have included a discussion of patients’ values for outcomes of options and support needs.6 It is also important to establish effective ways to make them easily accessible to patients, including low-literacy groups. For example, researchers at Baylor College of Medicine are testing the use of a “soap opera” approach for the presentation of information on breast cancer treatment decisions within video-formatted patient decision aids.84 Finally, patient decision aids will need to have routine updating built into the development process to ensure that they capture emerging evidence as it becomes available.

Although the value of patient decision aids has been clearly demonstrated in many areas of health care, including oncology, they have not become part of routine practice. Known barriers include limited health care professional skill in shared decision making and decision coaching, lack of awareness of patient decision aids, and limited number of available patient decision aids. Also, a fundamental change from the traditional doctor-patient roles is needed so that the new roles for both clinicians and patients are recognized instead of reliance solely on the clinician’s opinion. Clinical practice models to best
support the introduction of shared decision making and patient decision aids within clinical practice are needed. The effect of legally mandating these interventions into the informed-consent process, as occurred in Washington state, is yet to be known. By creating an environment where patients expect to be supported in decision making and making it easy for clinicians to prescribe standardized patient decision aids, we are more likely to incorporate these interventions as part of routine quality health care.

SUMMARY

Patients want to be involved in health decisions. Given the preference-sensitive nature of many oncology treatment or screening decisions, it is essential to use decision-making approaches that acknowledge patients’ informed values. To support their involvement in decision making, patients need access to clinicians skilled in shared decision making and effective interventions such as question prompt sheets, consultation planning, patient decision aids, and decision coaching. Considerable effort is required to ensure that shared decision making and effective interventions to facilitate this process are incorporated into oncology care pathways and informed-consent processes. The goal is to achieve high-quality decisions by balancing patient autonomy with clinician expertise, encouraging open dialogue between patients and their oncology team, and sharing in the responsibility for these decisions.

REFERENCES

1. Wennberg JE. Unwarranted variations in health-care delivery: implications for academic medical centres. BMJ 2002;325:961–964.
2. O’Connor AM, Drake ER, Wells GA, et al. A survey of the decision-making needs of Canadians faced with complex health decisions. Health Expect 2003;6:97–109.
3. Elwyn G, O’Connor A, Stacey D, et al. Developing a quality criteria framework for patient decision aids: online international Delphi consensus process. BMJ 2006;333:417.
4. Sepucha KR, Fowler FJ Jr, Mulley AG Jr. Policy support for patient-centered care: the need for measurable improvements in decision quality. Health Aff (Millwood) 2004;Suppl Web Exclusives: VAR54–VAR62.
5. Ratliff A, Angell M, Dow RW, et al. What is a good decision? Eff Clin Pract 1999;2:185–197.
6. Guimond P, Bunn H, O’Connor AM, et al. Validation of a tool to assess health practitioners’ decision support and communication skills. Patient Educ Couns 2003;50:235–242.
7. Elwyn G, Hutchings H, Edwards A, et al. The OPTION scale: measuring the extent that clinicians involve patients in decision-making tasks. Health Expect 2005;8:34–42.
8. Loh A, Simon D, Hennig K, et al. The assessment of depressive patients’ involvement in decision making in audio-taped primary care consultations. Patient Educ Couns 2006;63:314–318.
9. Stevenson FA, Cox K, Britten N, Dundar Y. A systematic review of the research on communication between patients and health care professionals about medicines: the consequences for concordance. Health Expect 2004;7:235–245.
10. O’Connor AM, Bennett C, Stacey D, et al. Do patient decision aids meet effectiveness criteria of the international patient decision aid standards collaboration? A systematic review and meta-analysis. Med Decis Making 2007;27:554–574.
11. Edwards A, Elwyn G. Inside the black box of shared decision making: distinguishing between the process of involvement and who makes the decision. Health Expect 2006;9:307–320.
12. Committee on Quality of Health Care in America, Institute of Medicine. Crossing the Quality Chasm: A New Health System for the 21st Century. Washington, DC: Institute of Medicine; 2001.
13. Registered Nurses’ Association of Ontario. Client Centred Care. 2006. Available at: http://www.rnao.org/Page.asp?PageID=924&ContentID=798. Accessed April 25, 2008.
14. Charles C, Gafni A, Whelan T. Shared decision-making in the medical encounter: what does it mean? (or it takes at least two to tango). Soc Sci Med 1997;44:681–692.
15. Mazur DJ. What should patients be told prior to a medical procedure? Ethical and legal perspectives on medical informed consent. Am J Med 1986;81:1051–1054.
16. Schultz EA. Informed consent: an overview. CRNA 1998;9:2–9.
17. Government of Ontario, Canada. Health Care Consent Act, 1996, S.O. 1996, c. 2, Sch. A.
18. Holmes-Rovner M, Wills CE. Improving informed consent: insights from behavioral decision research. Med Care 2002;40(suppl):V30–V38.
19. Magee M. Relationship-based health care in the United States, United Kingdom, Canada, Germany, South Africa, and Japan: a comparative study of patient and physician perceptions worldwide. Paper presented at: World Medical Association General Assembly; 2003; Helsinki, Finland.
20. Coulter A, Jenkinson C. European patients’ views on the responsiveness of health systems and healthcare providers. Eur J Public Health 2005;15:355–360.
21. Davison BJ, Gleave ME, Goldenberg SL, et al. Assessing information and decision preferences of men with prostate cancer and their partners. Cancer Nurs 2002;25:42–49.
22. Degner LF, Kristjanson LJ, Bowman D, et al. Information needs and decisional preferences in women with breast cancer. JAMA 1997;277:1485–1492.
23. Hack TF, Degner LF, Watson P, Sinha L. Do patients benefit from participating in medical decision-making? Longitudinal follow-up of women with breast cancer. Psychooncology 2006;15:9–19.
24. Street RL Jr, Voigt B. Patient participation in deciding breast cancer treatment and subsequent quality of life. Med Decis Making 1997;17:298–306.
25. Providing high quality, affordable health care to Washingtonians based on the recommendations of the blue ribbon commission on health care costs and access. SB 5930, Washington State (2007).
26. Bruea E, Willey JS, Palmer JL, Rosales M. Treatment decisions for breast carcinoma: patient preferences and physician perceptions. Cancer 2002;94:2076–2080.
27. Bruea E, Sweeney C, Calder K, et al. Patient preferences versus physician perceptions of treatment decisions in cancer care. J Clin Oncol 2001;19:2883–2885.
28. Mazur DJ, Hickam DH. Patients’ preferences for risk disclosure and role in decision making for invasive medical procedures. J Gen Intern Med 1997;12:114–117.
29. Brown RF, Butow PN, Henman M, et al. Responding to the active and passive patient: flexibility is the key. Health Expect 2002;5:236–245.
30. Towle A, Godolphin W. Framework for teaching and learning informed shared decision making. BMJ 1999;319:766–771.
31. Elwyn G, Charles C. Shared decision making: the principles and the competences, in Edwards A, Elwyn G (eds). Evidence-based Patient Choice. Inevitable or Impossible? Oxford, UK: Oxford University Press; 2001:118–143.
32. Gravel K, Légaré F, Graham ID. Barriers and facilitators to implementing shared decision-making in clinical practice: a systematic review of health professionals’ perceptions. Implement Sci 2006;1:116.
33. Butow P, Harrison JD, Choy ET, et al. Health professional and consumer views on involving breast cancer patients in the multidisciplinary discussion of their disease and treatment plan. Cancer 2007; 110:1937–1944.
34. Elkin EB, Kim SH, Casper ES, et al. Desire for information and involvement in treatment decisions: elderly cancer patients' preferences and their physicians' perceptions. J Clin Oncol 2007;25: 5275–5280.
35. Kleeberg UR, Feyer P, Günther W, Behrens M. Patient satisfaction in outpatient cancer care: a prospective survey using The PASQOC(R) questionnaire. Support Care Cancer 2008 Jan 17;[Epub ahead of print] PMID: 18322707.
36. Fowler FJ Jr, McNaughton Collins M, Albertsen PC, et al. Comparison of recommendations by urologists and radiation oncologists for treatment of clinically localized prostate cancer. JAMA 2000;283:3217–3222.
37. O’Connor AM. Validation of a decisional conflict scale. Med Decis Making 1995;15:25–30.
38. Sun Q. Predicting Downstream Effects of High Decisional Conflict: Meta-analysis of the Decisional Conflict Scale [master's thesis]. Ottawa, Ontario: University of Ottawa; 2004.
39. Gattellari M, Ward JE. Men’s reactions to disclosed and undisclosed opportunistic PSA screening for prostate cancer. Med J Aust 2005;182: 386–389.
40. O’Connor AM. Predicting downstream effects of high decisional conflict. Presented at: 3rd International Shared Decision Making Conference; June 2005; Ottawa, Canada.
41. Collins D-Sepucha K, O’Connor A, et al. Can women with early stage breast cancer make an informed choice for mastectomy? Presented at: 4th International Shared Decision Making Conference; May 2007; Freiburg, Germany.
42. Murray MA, O’Connor AM, Fiset V, Viola R. Women’s decision-making needs regarding place of care at end of life. J Palliat Care 2003;19:176–184.
43. Fiset V, O’Connor AM, Evans W, et al. Development and evaluation of a decision aid for patients with stage IV non-small cell lung cancer. Health Expect 2000;3:125–136.
44. Kinnersley P, Edwards A, Hood K, et al. Interventions before consultations for helping patients address their information needs. Cochrane Database Syst Rev 2007;3:CD004565.
45. Gaston CM, Mitchell G. Information giving and decision-making in patients with advanced cancer: a systematic review. Soc Sci Med 2005;61: 2252–2264.
46. Clayton JM, Butow PN, Tattersall MH, et al. Randomized controlled trial of a prompt list to help advanced cancer patients and their caregivers to ask questions about prognosis and end-of-life care. J Clin Oncol 2007;25:715–723.
47. Sepucha KR, Belkora JK, Aviv C, et al. Improving the quality of decision making in breast cancer: consultation planning template and consultation recording template. Oncol Nurs Forum 2003;30:99–106.
48. Belkora J, Katapodi M, Moore D, et al. Evaluation of a visit preparation intervention implemented in two rural, underserved counties of Northern California. Patient Educ Couns 2006; 64:350–359.
49. Sepucha KR, Belkora JK, Mutchnick S, Esserman LJ. Consultation planning to help breast cancer patients prepare for medical consultations: effect on communication and satisfaction for patients and physicians. J Clin Oncol 2002;20:2695–2700.
50. O’Connor AM, Rostom A, Fiset V, et al. Decision aids for patients facing health treatment or screening decisions: systematic review. BMJ 1999;319:731–734.
51. Goel V, Sawka CA, Thel EC, et al. Randomized trial of a patient aid for choice of surgical treatment for breast cancer. Med Decis Making 2001;21:1–6.
52. Street RL, Voigt B, Geyer C Jr, et al. Increasing patient involvement in choosing treatment for early breast cancer. Cancer 1995;76:2275–2285.
53. Whelan T, Levine M, Willan A, et al. Effect of a decision aid on knowledge and treatment decision making for breast cancer surgery: a randomized trial. JAMA 2004;292:435–441.
54. Green MJ, Bieseker BB, McInerney AM, et al. An interactive computer program can effectively educate patients about genetic testing for breast cancer susceptibility. Am J Med Genet 2001;103: 16–23.
55. Green MJ, Peterson SK, Baker MW, et al. Effect of a computer-based decision aid on knowledge, perceptions, and intentions about genetic testing for breast cancer susceptibility: a randomized controlled trial. JAMA 2004;292:442–452.
56. Lerman C, Bieseker B, Benkendorf JL, et al. Controlled trial of pretest education approaches to enhance informed decision-making for BRCA1 gene testing. J Natl Cancer Inst 1997;89:148–157.
57. Miller SM, Fleshler L, Rousi Pet et al. Facilitating informed decision making about breast cancer risk and genetic counseling among women calling the NCI’s Cancer Information Service. J Health Commun 2005;10(suppl):119–136.
58. Schwartz MD, Benkendorf J, Lerman C, et al. Impact of educational print materials on knowledge, attitudes, and interest in BRCA1/BRCA2: testing among Ashkenazi Jewish women. Cancer 2001;92:932–940.
59. van Roosmalen MS, Stalmeier PE, Verhoef LC, et al. Randomized trial of a shared decision-making intervention consisting of trade-offs and individualized treatment information for BRCA1/2 mutation carriers. J Clin Oncol 2004;22:3293–3301.
60. Whelan T, Sawka C, Levine M, et al. Helping patients make informed choices: a randomized trial of a decision aid for adjuvant chemotherapy in lymph node-negative breast cancer. J Natl Cancer Inst 2003;95:581–587.
61. Dolan JG, Fristau S. Randomized controlled trial of a patient aid for colorectal cancer screening. Med Decis Making 2002;22:125–139.
62. Pigonne M, Harris R, Kinsinger L. Videotape-based decision aid for colon cancer screening. A randomized, controlled trial. Ann Intern Med 2000;133:761–769.
63. Wolf AM, Schorling JB. Does informed consent alter elderly patients’ preferences for colorectal cancer screening? Results of a randomized trial. J Gen Intern Med 2000;15:24–30.
64. Auvine A, Hakama M, Alas-Opas M, et al. A randomized trial of choice of treatment in prostate cancer: the effect of intervention on the treatment chosen. BJU Int 2004;93:52–56.
65. Davison BJ, Degner LF. Empowerment of men newly diagnosed with prostate cancer. Cancer Nurs 1997;20:187–196.
66. Frosch DL, Kaplan RM, Feltiti V. The evaluation of two methods to facilitate shared decision making for men considering the prostate-specific antigen test. J Gen Intern Med 2001;16:391–398.
67. Gattellari M, Ward JE. Does evidence-based information about screening for prostate cancer enhance consumer decision-making? A randomised controlled trial. J Med Screen 2003;10:27–39.
68. Gattellari M, Ward JE. A community-based randomised controlled trial of three different educational resources for men about prostate cancer screening. Patient Educ Couns 2005;57:168–182.
69. Myers RE, Daskalakis C, Cocroft J, et al. Preparing African-American men in community primary care practices to decide whether or not to have prostate cancer screening. J Natl Med Assoc 2005;97:1143–1154.
70. Partin MR, Nelson D, Radosavie D, et al. Randomized trial examining the effect of two prostate cancer screening educational interventions on patient knowledge, preferences, and behaviors. J Gen Intern Med 2004;19:835–842.
71. Schapira MM, VanRuyswyk J. The effect of an illustrated pamphlet decision-aid on the use of prostate cancer screening tests. J Fam Pract 2000; 49:418–424.
72. Volk RJ, Case AR, Spann SJ. A randomized controlled trial of shared decision making for prostate cancer screening. Arch Fam Med 1999; 8:333–340.
73. Wolf AM, Nasser JF, Wolf AM, Schorling JB. The impact of informed consent on patient interest in prostate-specific antigen screening. Arch Intern Med 1996;156:1333–1336.
74. Stacey D, Murray MA, Légaré F, et al. Decision coaching to support shared decision making: a framework, evidence, and implications for nursing practice, education, and policy. Worldviews Evid Based Nurs 2008;5:25–35.
75. Kennedy AD, Schuler MJ, Coulter A, et al. Effects of decision aids for menorrhagia on treatment choices, health outcomes, and costs: a randomized controlled trial. JAMA 2002;288: 2701–2708.
76. Wirmann E, Ashkan J. Implementing Patient Decision Aids in Urology. Oxford, UK: Picker Institute Europe; 2006.
77. Graham ID, Logan J. Innovations in knowledge transfer and continuity of care. Can J Nurs Res 2004;36:89–103.
78. Stacey D, O’Connor A. Cochrane Inventory of Existing Patient Decision Aids Identified Using Cochrane Review Methods. Available at: http://decisionaid.ohri.ca/index.html. Accessed April 25, 2008.
79. O’Connor AM, Wennberg JE, Légaré F, et al. Toward the ‘tipping point’: decision aids and informed patient choice. Health Aff (Millwood) 2007;26:716–725.
80. Silvia KA, Sepucha KR. Decision aids in routine practice: lessons from the breast cancer initiative. Health Expect 2006;9:255–264.

81. Kearing S, O’Connor AM, Collins D, et al. Psychometric properties of a 10-item decisional conflict scale in a cohort of newly diagnosed breast cancer patients. Presented at: Society for Medical Decision Making Annual Conference; October 2006; Boston, MA.

82. Brackett CD, Cochran N, Coultermarsh M, et al. Assessing quality of the PSA screening decision: integrating shared decision making into primary care. Presented at: 30th Annual Meeting of the Society of General Internal Medicine; April 2007; Toronto, Canada.

83. Brooks B, Brackett C, Cochran N, Coultermarsh M. Integrating cancer screening decision aids into primary care: results of a pilot study. Presented at: Society for Medical Decision Making Annual Conference; October 2006; Boston, MA.

84. Jibaja-Weiss ML, Volk RJ, Granch TS, et al. Entertainment education for informed breast cancer treatment decisions in low-literate women: development and initial evaluation of a patient decision aid. J Cancer Educ 2006;21:133–139.