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## Decision Aids as a Guide for Cancer Patients Making Clinical Decisions

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### LEARNING OBJECTIVES

After completing this activity, the reader should be better able to:

- Cite examples of preference-sensitive decisions patients with cancer may face.
- Explain the benefits of a shared decision-making approach.
- Describe interventions that have been used to promote patient involvement in clinical decision making.

### TARGET AUDIENCE

Advanced practice nurses, registered nurses, and other interested healthcare professionals, especially those caring for cancer patients.

### COST

This program is complimentary for all learners.

Clinical decision making by cancer patients is a complex process. While it is widely accepted that impressive advances over the past decade have led to disease-specific guidelines and clinical pathways for some cancers, which makes decision making fairly straightforward, many decisions are preference-sensitive and therefore more difficult. Some examples of preference-sensitive decisions for patients with cancer are:

- Use of tamoxifen for prevention of breast cancer
- Genetic testing
- Prostate-specific antigen screening
- Treatment for early-stage breast and prostate cancer
- When to stop active treatment
- Location of end-of-life care.

To make preference-sensitive cancer decisions, oncology care providers need to assess patients' values for benefits and harms across cancer screening and/or treatment options. Because there is no such thing as a "best choice" for everyone, decisions are defined as being of superior quality when they are based on current scientific evidence and take into account patients' informed values and preferences.<sup>1-3</sup>

Unfortunately, there are multiple obstacles to high-quality decision making. For example, evidence seems to suggest that standard counseling in clinical practice does not produce high-quality decisions.<sup>4-7</sup> In

addition, although patients have a variety of means for accessing multiple sources of medical information, they often lack the breadth of knowledge or the confidence needed to be able to assess screening and treatment options effectively. They also may have unrealistic expectations as well as decisional conflict that thwart effective decision making.

Patients exposed to decision aids are more likely to be involved in decision making. Patient involvement in decision-making processes, in turn, can boost patient satisfaction, understanding, and confidence in the decisions that are made, and ultimately contribute to better-quality decisions.

### Shared decision making

Until recently, physicians and their "designates" were the sole providers of medical information and therefore the sole decision makers; a practice referred to as a "paternalistic model." Over the past decade, however, with improved access to medical information, patients have become increasingly involved in clinical decision making. A shared decision-making approach in which patients discuss with their clinicians current evidence on treatment options and make a mutually agreed-on choice offers several benefits:

- It provides individualized patient-centered care
- It complies with legal and ethical patient rights

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- Dawn Stacey, RN, MScN, PhD, CON(C), is a consultant for Ortho Biotech Canada involved in patient decision aid development for patients with psoriasis, and receives grant/research support from the Foundation for Informed Medical Decision Making.

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## Clinicians need to use an individualized approach when determining whether a patient seeks to participate in decision making, and, if so, to what extent.

- It addresses the patient's desire to be involved
- It is accountable for screening and treatments used
- It improves patient satisfaction with the decision-making process
- It can potentially improve patient health outcomes.

Despite these benefits, many clinicians have not adopted the practice of shared decision making.<sup>8</sup> Oncologists, in particular, often do not encourage patient involvement to the extent that patients would like.<sup>9-11</sup> It may be that oncologists underestimate the extent to which their patients want to be involved in the decision-making process.<sup>5,6</sup> Patient preferences are hard to predict, given that there do not seem to be any factors proven to correlate with patient preferences or preferred role in decision making. Thus, clinicians need to use an individualized approach when determining whether a patient seeks to participate in decision making, and, if so, to what extent.<sup>12,13</sup>

### Interventions to promote patient involvement in decision making

An array of interventions is available that aim to boost patient involvement in the decision-making process. The best interventions are those that help patients recognize that a decision needs to be made, understand the scientific evidence currently available, and clarify their values associated with the outcomes of screening and treatment options—all of which should help produce a top-quality decision.<sup>1</sup> Conventional patient education materials have not proved to be sufficient. The following options have all demonstrated benefit.

**Patient decision aids.** These are tools that translate evidence into patient-friendly form by providing, at a minimum, information on the options, risks and benefits of screening and treatment options, and implicit methods to clarify personal values.<sup>14</sup> Values can be clarified implicitly by providing details on what it is like to undergo the procedures and to live with the physical, social, and emotional consequences in a way that makes it possible for patients to formulate personal value judgments. Decision aids also may include information on the medical condition and the likelihood of the benefits and risk of the various options. Patient decision aids are usually self-administered and are available in several patient-friendly formats, for example, as paper handouts, videos or DVDs, or computer software. Some decision aids are administered by the practitioner and may involve more complex approaches. Given the relative ease of updating information and minimal dissemination costs, the Internet has become the primary resource for patient decision aids.

We reviewed 23 randomized controlled trials that focused on cancer-related decisions such as prostate and colon cancer screening, breast cancer genetic testing, and breast and prostate cancer treatment.<sup>15</sup> The 23 trials were drawn from the 55 randomized controlled trials included in the Cochrane systematic review of patient decision aids.

Overall, patient decision aids were shown to consistently improve knowledge, decrease decisional conflict, and lead to choices that were compatible with patients' values.<sup>15</sup> When we compared cancer-specific decision aids with usual care, we found that individu-

als who received patient decision aids were more likely to participate in decision making and were better informed than persons not receiving such aids. Patients exposed to cancer-specific decision aids that included descriptions of outcomes and probabilities more often had accurate risk perceptions than those who did not receive this information. Cancer-specific decision aids also can prevent overuse of some aggressive interventions as well as underuse of other interventions.

Although patient decision aids have been shown to be useful in oncology, they have not been routinely incorporated into oncology practices. Common obstacles to the use of these aids include a lack of skills among healthcare professionals in shared decision making, a lack of awareness of patient decision aids, and availability of patient decision aids on a limited number of decisions.<sup>16</sup>

**Question prompt sheets.** These are standardized sets of questions that guide patients on how to obtain information during the consultation.<sup>17</sup>

**Consultation planning.** This is a process whereby trained facilitators coach patients on how to develop their own list of questions to ask during their

consultation. Trained facilitators are usually nurses, patient navigators, or individuals who work at the resource center.<sup>18</sup>

**Decision coaching.** Decision coaching facilitates patient involvement in decision making.<sup>19</sup> Decision coaches are health professionals who assess patients' decisional conflict and related needs, guide patients through the decision-making process using decision aids and/or evidence-based information, and monitor for factors that can influence the patient's implementation of the shared decision.

### Future research

Although cancer patients are seeking increased participation in clinical decision making with the ultimate goal of achieving better clinical decisions, more research is needed to help achieve these goals. Future studies are needed to:

- assess the impact of patient decision aids on patient-clinician communication
- identify ways to overcome barriers to the adoption of patient decision aids by routine oncology practices
- determine effective ways to make patient decision aids easily accessible to patients
- explore the implications of legally requiring that these interventions be included in the informed consent process
- establish effective approaches to help oncologists and patients transition from the standard paternalistic doctor-patient model to a shared decision-making model.

## COMMENTARY

### Decision Aids as a Guide for Cancer Patients Making Clinical Decisions: A Nurse's Perspective

BY SHARON GENTRY, RN, MSN, AOCN

Derrick L. Davis Forsyth Regional Cancer Center, Winston-Salem, North Carolina

The article by Stacey and colleagues reminds healthcare professionals of the transition from paternalistic patient non-decision making that our oldest patients may have experienced to the current active participation in medical decision making that our patients currently face in many healthcare settings.

Teamwork is essential for a satisfactory and high-quality medical journey for the patient. The patient brings to the shared decision-making process his or her knowledge, whether it is basic understanding of their disease or extensive understanding of treatment choices. This knowledge is colored with the patient's values and culture. Healthcare professionals bring the current scientific evidence to best treat the specific disease, which the patient needs to understand to make a high-quality decision about his or her care.

Patient decision aids are the common link and solution to merge the team together. Although, as Stacey and colleagues discuss, studies have shown that decision aids can improve patients' knowledge and help them make informed decisions about their care, they are not widely used in oncology practices. It takes a commitment from

the healthcare staff to make patients aware of appropriate decision aids, become skilled in using them, and make time for a shared decision consultation. The patient must invest time to complete the aids prior to consultation.

It is important to point out that a decision tool is not simply a patient education sheet or other teaching material that is intended solely to increase a patient's knowledge base. For example, a chemotherapy teaching sheet is not a decision aid. A question prompt sheet is not meant to be used alone but instead as a guide to address what information the patient needs. An example of a decision aid available on the Internet is Cancer NexProfiler ([www.oncolink.upenn.edu](http://www.oncolink.upenn.edu)). This is a free, interactive tool that allows a patient to get information about treatment options and outcomes that can be discussed with the healthcare team.

As healthcare professionals, we need to stay on the learning curve and increase our personal awareness of current decision aids that may be beneficial for patients. To ensure quality decision making by our patients, the decision aids should be used early during the patient's medical journey.

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## Conclusion

Public surveys consistently indicate that people want to be involved in health decisions. However, when faced with values-sensitive decisions related to cancer screening and treatment, current clinical counseling is inadequate and patients need guidance to gain their desired role in decision making. Interventions to support patients' involvement in decision making include patient decision aids, question prompt sheets, consultation planning, and decision coaching. Healthcare professionals have an important role in assessing factors influencing patients' decision-making needs, providing support to address their needs by using effective interventions, and monitoring patients' progress in making and implementing decisions.

## Case Report

### Decision Coaching for Man with Early-stage Prostate Cancer

A 51-year-old patient, recently diagnosed with early-stage prostate cancer by his urologist, was given educational material regarding treatment options and booked for a follow-up visit. When the oncology nurse did an initial assessment, she found that although Mr Smith felt that he had enough information about his options, he was not sure which option was best for him, primarily because he felt unclear about which risks and benefits of options were most important. The dialogue that

ensued clarified that, for Mr Smith, the benefit of treatment—increased chance of survival for men under age 65—outweighed the side effects of treatment and that he wanted to seek active treatment versus watchful waiting. He was still undecided regarding the best treatment option (radiation or surgery). The following dialogue provides an overview of the decision support that was provided in preparation for discussion with the urologist.

### Clarify the options and their benefits

"You are correct that the chance of cure is about the same for both radiation and surgery, and you seem to have a good sense of what is involved with these treatments. At this point, it would help if you could think about the side effects of these treatments and determine which ones are more important for you to avoid. Would it help if I reviewed these side effects and the chance that they will occur?"

### Side effects of options

"There are three main side effects of prostate cancer treatments. Bladder problems are more likely to occur with surgery; bowel irritation is more likely to occur with radiation; and impotence can occur to differing degrees with both options. For bladder problems, research shows that if 100 men like you had surgery, about 10 to 20 men would have bladder problems, such as dribbling or leaking of urine. For bowel irritation, if 100 men like you had radiation, about 30 men

would have bowel irritation, such as diarrhea during treatment, but only five to 10 men will have longer-term diarrhea and need to be more careful about what they eat. Impotence can occur in at least half of the patients regardless of the treatment. The difference is that you will know if you are impotent within days after surgery and, if you are, it is usually permanent; for radiation therapy, the impotence has a more gradual onset and may not be permanent."

### Clarify patient values

"Have you thought about what it means to live with possible side effects of treatment such as urinary dribbling, impotence, or diarrhea from bowel irritation? Is there one that is more important for you to avoid?"

### Screen for decisional difficulties

"Now that we have discussed the different options, are you leaning toward one treatment more than another, or is there anything else that you would like to discuss?"

Given his active lifestyle and the possible impact on sexual relations, Mr Smith clearly preferred to live with the potential complications of radiation and avoid the chance of urinary dribbling and impotence associated with surgery. ●

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Jill Stein contributed to the preparation of this manuscript.

## COMMENTARY

### Decision Aids as a Guide for Cancer Patients Making Clinical Decisions: A Pharmacist's Perspective

BY PATRICK MEDINA, PHARMD, BCOP

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Pharmacists tend to be data driven, often forgetting the importance of including patients in the decision-making process. It is often assumed that patients will want the treatment dictated by the literature using "evidence-based medicine." However, the "data" often contradict this perception. Several surveys note that patients' willingness to undergo treatment as well as their tolerability of certain cancer-related adverse effects is different from healthcare professionals' perceptions.

The article by Stacey and colleagues reminds healthcare professionals that the medical information boom largely found on the Internet requires healthcare professionals to transition from paternalistic patient non-decision making to a shared decision-making approach.

Stacey and colleagues point out that current oncology practices have not routinely adopted this approach, despite several benefits cited in the article. Patients who use these aids were better informed and more involved in their decision making—a goal that most practices should welcome. One reason is that conventional patient education materials may not be sufficient to do the job. This is an area where pharma-

cists should use their expertise and improve the resources available.

Because most patient decision aids are self-administered and available on the Internet, healthcare professionals, including pharmacists, can assist patients in finding well-validated decision aids that will be useful for their particular disease state. For instance, patients can use [www.collaborativecare.net](http://www.collaborativecare.net) to assist them in making decisions about their breast cancer treatment.

In summary, the article by Stacey and colleagues highlights the importance of clinical practices incorporating a shared decision-making approach to improve their patients' care. Although current tools have limitations, several have shown benefit in assisting patients who are making difficult decisions, and often the results contradict conventional wisdom. Pharmacists can assist this process by guiding patients to appropriate tools as well as improving the decision-making tools currently available.

As individualized care increases with genetic testing and pharmacogenomic profiling, use of decision-making tools will increase. These tools will need to be incorporated into clinical practice by healthcare professionals, including pharmacists.