

Putting shared decision making to work in breast and prostate cancers: tools for community oncologists

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A diagnosis of prostate or breast cancer throws patients into a state of cognitive and emotional overload. Patient anxiety and confusion can be exacerbated when there is no single dominant treatment, but rather multiple treatment options that require patients and oncologists to make trade-offs between benefits and harms. Patients rely on their oncologists to guide them to good decisions. There are an increasing number of tools available to help oncologists engage and educate their patients before, during, and after consultations. We discuss four tools that are available to community oncology practices: decision aids; prompt sheets; knowledge and preference surveys; and structured consultation notes. Community oncologists may wish to adapt and implement these tools in their practices to help their patients make informed choices.

A diagnosis of breast or prostate cancer comes as a shock. Patients usually have no symptoms. They are quickly thrust from their regular lives, with work and family responsibilities, into the medical world of tests, doctor's visits, and treatments. Fortunately, most breast and prostate cancer diagnoses are not emergencies, and there is time for patients to adjust, with support from the people around them. Unfortunately, when they get past the initial shock, many breast and prostate cancer patients learn that there isn't one best treatment for their condition. Guidelines and consensus criteria recognize the appropriateness of multiple options, with the best choices to be guided by both medical evidence and the patient's own preferences.¹⁻³ From the medical perspective, having this range of choices may represent a significant advance. But when doctors cannot recommend one "best" treatment, patients often feel anxious, conflicted, and confused.

Over the past few decades, there has been a distinct shift away from paternalistic medicine. For example, women no longer undergo surgery without knowing whether they will wake up with or without a breast. However, the emphasis on consumer-driven health care has created its own set of problems. Patients facing cognitive and emotional overload may not be in the best position to be making life-altering decisions. So a middle ground

has emerged. Now there is a more collaborative approach to medical decision making that takes into account the importance of both providers and patients in the process.⁴⁻⁸

KEY POINTS

Decision aids—tools that provide easy-to-understand information on disease and diagnosis based on the latest evidence—can be sent to patients prior to consultation with the oncologist.

Prompt sheets allow the patient to write down important questions, concerns, and objectives prior to consultation, enhancing the likelihood of effective communication during the office visit.

Written responses to the specific items on the prompt sheet can serve as a patient-friendly take-home summary of the consultation.

Instruments that use probe statements (eg, "How important is it to you to avoid problems with sexual function?") can help clarify patient preferences and identify gaps in understanding of risks/benefits of potential treatment.

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TABLE 1

Breast cancer decision aids available through the Foundation for Informed Medical Decision Making

- Treatment Choices for DCIS
- Early-stage Breast Cancer: Choosing Your Surgery
- Breast Reconstruction: Is it Right for You?
- Early Breast Cancer: Chemotherapy and Hormone Therapy
- Living with Metastatic Breast Cancer: Making the Journey Your Own

Here, we report on some tools and techniques that providers can use with patients to promote a shared approach to making treatment decisions. These practices have been proven to make a difference in the quality of decisions⁹ and in health and quality-of-life outcomes.^{10,11} Different versions and combinations of these tools have been adopted by several academic centers and are starting to be used in community settings as well. Oncologists may consider adapting and incorporating some or all of them into their routine clinical practice to help their patients make informed choices.

Educational materials for decision making

With the increasing number of options available, a large part of the patient/physician consultation is spent educating patients about treatments and their benefits and harms. As information has become more widely available, precious time during office visits is spent readjusting or correcting mistaken beliefs gleaned from the

DECISION AIDS are available on the Web, as booklets, videotapes, or audiotapes, or as combinations of these media. A list of decision aids for all diseases, including cancer, can be found at the University of Ottawa (<http://decisionaid.ohri.ca/AZinvent.php>); many of them are free or available at low cost.

Internet and other sources. Because most cancer patients don't comprehend or retain much from their initial visit, it has become necessary to continue educating them.

Oncologists need to develop strategies to provide screened, targeted, and accessible information to their patients before, during, and after consultations. Most oncologists already distribute some materials to their patients, such as booklets from the American Cancer Society or National Cancer Institute. A few practices are sending patients materials targeted to their diagnosis before the visit, to help them prepare. Others provide lists of approved Web sites and books, or have nurses, for example, offer patient education through group or individual sessions.

Of particular value are decision aids, tools that provide easy-to-understand information based on the latest evidence. Most cancer decision aids have been developed for breast and prostate cancers. Some of these aids have been shown to increase patients' knowledge, reduce the conflict associated with decision making, and help patients make treatment choices.⁹⁻¹²

The Foundation for Informed Medical Decision Making has produced five decision aids for breast cancer patients (see Table 1) available on video or DVD with an accompanying booklet. Each program presents timely information on factors important to decision making through interviews with providers and also provides vicarious experience through interviews with patients who talk about their decisions and their experiences with treatments. Copies of the programs are available to oncologists free of charge (contact the authors or bcaprogram@fimdm.org for more information). These programs are being used in close to 50 academic and community cancer centers across the country. Patients use the programs before their consultation with the surgeon or oncologist. At most of the sites using the programs, a nurse or social worker

provides the programs to patients before they see the doctor. At a few sites, the doctors give the programs to patients directly. Some sites have reached large numbers of patients by integrating the programs into their clinical pathway as a routine part of care.¹³

Prompt sheets to help patients prepare questions

Decision aids and other educational materials are helpful in giving patients information and providing structure for thinking about decisions, but patients also need information specific to their situation. Getting such information is not always straightforward. Most patients have had the experience of forgetting questions they wanted to ask while in the doctor's office or of thinking of questions they wished they had asked after they leave. Many patients feel anxious about interrupting their doctor even when they have specific questions in mind. And, with the increasing demands on their time, many doctors do not leave adequate time for patients to ask questions.

Evidence suggests that simply giving patients a prompt sheet to write down their questions can lead to improved interactions and outcomes.¹⁴⁻¹⁷ The prompt sheets can be based on frequently asked questions, such as those identified by the National Cancer Institute in a review of cancer patient information needs.¹⁸ Or, they can be organized according to conceptual models of decision making.^{19,20}

One example of such an instrument is the SCOPED prompt sheet, which prompts patients to think about questions and concerns regarding:

- Situation—the diagnosis and other aspects that may affect decisions and choices, such as comorbidities;
- Choices—all the different options available, including further testing or clinical trials;
- Objectives—the goals and values that are most important to the patient;
- People—the other people involved in decision making and those affected

by the choices;

- Evaluation—the benefits and harms of each choice and how the choices affect the objectives;

- Decisions—which option is best, and what are the next steps.

Table 2 illustrates a completed SCOPED sheet for a man deciding about treatment for prostate cancer. A number of resource centers and one academic medical center in Northern California have adopted the SCOPED prompt sheet.²¹ At these sites, patients work with staff or volunteer peer navigators, health coaches, or educators to respond to the prompts and bring their questions and concerns to the consultation. The staff or volunteers are trained to administer the prompt sheets in a way that facilitates brainstorming of questions and concerns, without the provision of information or advice.²² A focused list of questions and concerns can help ensure that patients get the information they need in conversation with their physician. The SCOPED prompt sheet is available at <http://www.guidesmith.org/questions-for-your-doctor/>. Another decision-focused prompt sheet, the Ottawa Personal Decision Guide, is available at <http://decisionaid.ohri.ca/decguide.html>.

SCOPED note: a summary of the visit

Having a record of what happens during a patient visit is important for both providers and patients. Many advocates recommend that patients audiotape the visit. Studies have shown that patients value these recordings, and that they may protect physicians from complaints and legal conflicts.^{10,23} However, the recordings don't provide a summary that can be easily reviewed or shared with family and friends, and providing such a summary is not a routine part of patient contact for most providers. Indeed, virtually all the documentation generated by a patient visit remains in the medical chart.

The authors and colleagues have proposed extending the use of the

TABLE 2

Example of a patient's completed prompt sheet that highlights questions and concerns related to the decision about treatment for localized prostate cancer

Topic

- George's questions and concerns for Dr. T

Situation

- Has the cancer spread outside the prostate?
- What is my stage—am I a 6 or 7?
- I have had urinary problems (benign prostate hyperplasia [BPH]) for several years and am taking medication.

Choices

- Am I a good candidate for radiation seeds?
- Do I need androgen deprivation?
- Do you do nerve-sparing surgery?

Objectives

- My wife wants me alive, but quality of life is important too. If possible, I would like to preserve sexual function and not worsen my urinary function.
- I am still working as a teacher and would like to continue (if urinary problems worsen, that could be difficult).
- We have a cruise planned for August that we would like to take.

People

- My wife and I are in this together.
- I trust the urologist. Is there anyone else I should see?

Evaluation

I need more information about benefits and harms:

- What is my prognosis with surgery? Radiation?
- What is the likelihood that I will be able to have sex after surgery or radiation?
- What can I expect for urinary function after each?
- What is the recovery like? How long will I need to be out of work?
- I take medications for heart disease and BPH, do I need to worry about interactions?

Decisions

- I want to make the decision today with my doctor's advice. I want to know the doctor's recommendation.
- I am leaning toward surgery since it is quickest. I don't think I could just watch and wait—I would be too anxious.
- How soon can we schedule surgery? Will I be able to go on the cruise?

SCOPED prompt sheet to serve as an agenda for the visit and using it to capture the nurse/oncologist's responses. This SCOPED note provides a patient-friendly take-home summary of the consultation. The summary does not need to capture all the details covered in the consultation; rather, it can focus on the oncologist's concluding information and advice, with particular attention given to answering patient's specific questions

and concerns. Table 3 shows how an oncologist or nurse might summarize the consultation for the prostate cancer patient completing the SCOPED prompt sheet as in Table 2. The patient's major questions and concerns are addressed and the information is captured concisely. The SCOPED note can be given to the patient to take home and can be used by the oncologist to document the consultation in the medical record.

TABLE 3

Example of a completed SCOPED note that addresses the issues raised in the patient's prompt sheet*

Topic

- Summary of George and Dr. T's consult

Situation

- The Gleason score is 6, and it is very unlikely that the cancer has spread outside the prostate.

Choices

- You may consider watching and waiting.
- Surgery, seeds, or external radiation are options.
- You are a candidate for newer techniques, nerve-sparing surgery, and laparoscopic surgery.
- You are not a good candidate for hormones.

Objectives

- There is flexibility for scheduling treatments around your commitments.
- See evaluation section, below, for details on outcomes and how treatments compare.

People

- It would be good for you to see a radiation oncologist to get more details on radiation, even if you don't end up taking it.

Evaluation

Prognosis

- Your prognosis is very good. Most likely you will die of something other than prostate cancer even without treatment (~85% 10-year survival).
- The data suggest that you have a very good chance of cure with surgery or radiation (~90% 10-year survival). There are not very good data on some of the newer techniques and treatments.

Side effects/complications

- Short term, surgery has a bigger impact on sexual function than radiation, but at 5 years the rates are about the same with either.
- After 2 years, the problems with urinary function are about the same with either.

Logistics/recovery

- After surgery, most men are in the hospital for less than a week and go home with a catheter in place that is removed after a week or two. In about 3 months, 60% of men are back to normal activities.
- Radiation is scheduled for 6–8 weeks. Some men are able to continue working during radiation, but it does require some flexibility with scheduling. Seeds might be better, since it is only one procedure, but I would want to talk to the radiation oncologist about your current urinary function.

Decisions

- Given your age (57), I would recommend some intervention.
- The best choice depends on how you feel about the benefits and harms of each.
- This is not an emergency, you can take several weeks or even months to decide. Call me if you have other questions or after you talk with the radiation oncologist to let me know what you have decided.
- It is possible to start treatment after you come back from the cruise, although that might require you to take time off at the beginning of the school year.

* This note can be printed and taken home by the patient as a summary of the visit. It can also supplement the dictated note in the medical record.

Instruments to probe patient knowledge and preference

Tools like the SCOPED prompt sheet and SCOPED note can provide structure to consultations, which is helpful to both patient and physician. However, patients often need to make specific decisions about treatment that involve their considering a large amount of information; it is helpful to use probe questions that can elicit patients' feelings about key facts and values inherent to each decision.

For example, consider the minimal amount of information that a patient should understand in making treatment decisions about localized prostate cancer:

- In general, most men with localized prostate cancer die of something else, with or without any treatment.
- For most men, there are three reasonable ways to treat it—surgery, radiation, or watchful waiting.
- There are few good data comparing the benefits and harms of the different management plans for early-stage prostate cancer, particularly prostate cancers discovered with a prostate-specific antigen (PSA) test.
- For men younger than age 75, surgery has been shown to improve survival compared with watchful waiting, at least for cancers discovered by digital rectal exams (rather than the PSA test).
- Active treatments, such as surgery and radiation, can cause problems with erections and urinary function.
- Watchful waiting, or no active treatment right away, can help men avoid or delay the side effects of surgery or radiotherapy until such time as the active treatment is clearly indicated.

Knowing this information alone may not lead to a best choice. It can be very helpful to have patients focus on specific outcomes to aid in decision making. Thus, for example, patients might be asked to rate on a scale of 1–10 (where 1 is not at all important and 10 is very important), the following items: "How im-

portant is it to do everything possible to avoid dying of prostate cancer?" "How important is it to avoid problems with dripping or leaking urine? With sexual function?" Answers to such questions can help discriminate among men who may prefer watchful waiting over active treatment. Additional items may help distinguish between men who want active treatment and are deciding between surgery and radiation, including newer techniques and procedures—such as "How important is it to avoid surgery?" "How important is it to avoid bowel problems?" "How important is it to finish treatment as quickly as possible?" "How important is it to use treatments that have been well tested?"

This type of assessment can be done informally during the conversation or administered as an instrument. The responses can be used as a screen to better diagnose gaps in patient understanding, assess patient priorities, and assess the patient's attitudes on the risk-benefit profiles of treatments.

The Foundation for Informed Medical Decision Making is funding the development of decision-specific knowledge and preference instruments for a wide range of conditions.²⁴ The aim of such instruments is not to exhaustively test patient knowledge, but rather to check whether patients grasp some of the key issues involved in their decision. The information can be used to guide quality improvement initiatives. For example, knowledge scores can be aggregated to determine whether patients are getting the key messages across various practice settings. Oncologists can thus answer questions such as: "Are early-stage breast cancer patients who have a strong preference for keeping their breast more likely to have breast conservation?" "Are prostate cancer patients who have a strong preference to avoid problems with sexual function more likely to forego active treatment?" Value concordance can be calculated to determine the strength of association between values and choices (see for example, Barry et al 1995²⁵).

Conclusion

Many oncologists are currently involved in efforts to improve the effectiveness of their communication with patients in order to promote informed choice.^{26–28} Many of these efforts focus on strengthening interpersonal communication skills or other skills used during the actual conduct of oncology consultations. Our experience indicates that there are also simple task-oriented tools and methods that oncologists can use before, during, and after oncology consultations to improve the quality of decision making with patients. We have presented four types of tools in this article. Some practices are already using combinations or variations of these tools. For each tool, we have indicated some practical resources aimed at helping in implementation. The tools are inexpensive (most are free), but oncologists wishing to implement them will have to invest some time in setting them up and integrating them into their practice.

These tools follow the common advice given by cancer survivors to newly diagnosed patients: "Learn about your condition; make a list of questions for your doctor; think about what's important to you; take notes or bring someone to take notes for you; make a tape recording of your consultation." These practices have indeed been proven to make a difference in the quality of patient care and in health and quality of life outcomes.^{10,11} However, left to their own devices, newly diagnosed patients may not be able to implement these best practices. Oncologists committed to improving the quality of care can adapt the tools discussed to help ensure that their patients are informed and that the treatments chosen reflect patients' preferences.

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