Decision Aids Help Patients but Still Are Not Widely Used

By Gunjan Sinha

Patient decision aids (PtDAs)—educational materials that explain patients’ options—help communicate probabilities and boost confidence in medical decisions. But few physicians use them.

“The barriers are a mile high,” said Glyn Elwyn, Ph.D., professor at the Dartmouth Center for Health Care Delivery Science in Hanover, N.H.

Elwyn co-wrote a study that investigated efforts to implement PtDAs in routine clinical settings (BMC Med. Inform. Decis. 2013;13 Suppl. 2:S14). Apart from Dartmouth-Hitchcock Medical Center in New Hampshire, Group Health Cooperative in Seattle, and a few comprehensive cancer care centers, adoption of PtDAs tools in the U.S. has been spotty, Elwyn said.

PtDAs can be pamphlets or charts to consider before a consultation, online fact sheets or quizzes that explore options, or materials containing charts and graphs to help physicians clarify risks and benefits. Although some companies sell these materials, most PtDAs are developed by academics and are freely available online.

Interest in PtDAs surged after research suggested they can reduce unnecessary procedures and cut costs. For example, among 45 women older than 75 years, eight chose not to have mammograms. But after reading a PtDA on the topic, 12%–21% drop in costs of patient care. For example, patients with early-stage prostate cancer must choose from active surveillance, radical prostatectomy, and radiation type. Thyroid cancer patients must decide whether to undergo radioactive iodine therapy. Whereas the doctor traditionally made such decisions, patients in “preference sensitive” decision making choose for themselves after evaluating risks and benefits.

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“We owe it to patients to give them data that they can understand,” said Angela Fagerlin, Ph.D., codirector of the Center for Bioethics and Social Sciences in Medicine at the University of Michigan—Ann Arbor. She wrote a commentary (J. Natl. Cancer Inst. 2011;103:1–8) highlighting 10 methods that improve patients’ understanding of risk and benefit information. PtDAs evolved to streamline doctor–patient communication and to promote shared decision making. More than 80 randomized clinical trials have shown that such tools benefit patients. They can also help doctors.

“They save me time,” said Thomas Smith, M.D., director of palliative care at the Hopkins Sidney Kimmel Comprehensive Cancer Center in Baltimore. Cancer clinicians there routinely use PtDAs in several settings, most commonly during consultations with breast cancer patients to discuss risks and benefits of various adjuvant therapies and outcomes, Smith said.

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Studies have shown, for example, that between two-thirds and three-fourths of patients with metastatic disease mistakenly think they can be cured with chemotherapy (N. Engl. J. Med. 2012; 367:1616–25). With a PtDA, “the chance of people being deluded is much smaller,” Smith said. “It helps patients plan ahead.”

Although several PtDA tools are available online, “as a field, we are still developing the standards of how this should be done,” said Paul Han, M.D., M.P.H., director of the Center for Outcomes Research and Evaluation in Portland, Maine. Han cowrote a review of guidelines that improve the quality of risk communication (BMC Med. Inform. Decis. 2013;13 Suppl. 2:S7).

A larger problem is getting them to patients: “There is no money to disseminate them,” Fagerlin said.

Although oncologists who treat breast cancer use PtDAs extensively, physicians treating other illnesses, including other types of cancer, have not embraced these tools. One reason could be oncologists’ reluctance to give bad news, Smith said. But “you don’t get any bonus survival points for denying the truth,” he added. Physicians have also cited having little confidence in the content of such tools as well as concerns about disrupting established workflows, Elwyn said.

Because academics develop most PtDAs, however, physicians associated with academic...
Institutions may have an easier time accessing them. The Hopkins cancer center works with several tools developed either in-house or in collaboration with researchers elsewhere. Smith is also working with the California Health Department to develop cancer-related PtDAs that could be freely available from the department’s website.

In the U.S., the 2010 Affordable Care Act includes a provision to help ensure broad adoption of decision aid tools.

Under Section 3506, the Secretary of the Department of Health and Human Services must establish a program that develops, tests, and disseminates certified PtDAs. The provision has not been funded, however, and action on it is frozen. Meanwhile, countries such as Canada, Australia, and the UK are working toward mandating routine use of such aids in clinics.

U.S. government funding and certification would help disseminate high-quality PtDAs more widely, Elwyn said. But tools are not enough, he added.

“We are talking about cultural and philosophical change in the health care system’s willingness to involve patients in health care decisions. We can make tools and disseminate them, but that will not change the culture quickly.”

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PDQ (Physician Data Query) is the National Cancer Institute’s source of comprehensive cancer information. It contains peer-reviewed, evidence-based cancer information summaries on treatment, supportive care, screening, prevention, genetics, and complementary and alternative medicine. The summaries are regularly updated by six editorial boards. The following PDQ summaries were recently updated:


The PDQ Genetics of Colorectal Cancer and the PDQ Genetics of Prostate Cancer summaries were recently updated to include the results of a study of 198 families in two U.S. Lynch syndrome registries that found an increased cumulative incidence and risk of prostate cancer among Lynch syndrome family members. Prostate cancer risk in relatives of mismatch repair gene mutation carriers was 6.3% at age 60 years and 30% at age 80 years compared with a population risk of 2.6% at age 60 years and 18% at age 80 years, with an overall hazard ratio (HR) of 1.99 (95% confidence interval [CI], 1.31–3.03; P = .0013). Among men aged 20 to 59 years, the HR was 2.48 (95% CI, 1.34–4.59; P = .0038). The authors suggested consideration of prostate cancer screening beginning at age 40 years in male mismatch repair gene mutation carriers, although additional studies are needed to assess the potential risks, benefits, and cost effectiveness of this screening. To review the summaries, please use the following links:

http://www.cancer.gov/cancertopics/pdq/genetics/prostate/HealthProfessional/Page3#Section_1234
http://www.cancer.gov/cancertopics/pdq/genetics/colorectal/HealthProfessional/Page3#Section_3


The PDQ Cancer Genetics Risk Assessment and Counseling summary was recently updated to state that advanced training in cancer genetics and genomics is needed among health professionals to increase competency in the following reported areas of deficit: (1) knowledge about hereditary cancer syndromes and risk-appropriate management strategies; (2) provision of genetic counseling services; (3) use of personal and family cancer history to identify and refer patients at increased risk of hereditary cancer syndromes; and (4) knowledge about genetic nondiscrimination. A table describing online genetics educational resources for health professionals is available in the PDQ Cancer Genetics Overview summary. To review the summaries, please use the following links:

http://www.cancer.gov/cancertopics/pdq/genetics/risk-assessment-and-counseling/HealthProfessional/Page2#Section_325
http://www.cancer.gov/cancertopics/pdq/genetics/overview/healthprofessional/Page7#Section_73

The PDQ Genetics of Skin Cancer summary was recently updated to include a new section on BRCA-associated protein 1 (BAP1), a tumor suppressor gene that has recently been implicated in both sporadic and hereditary melanomas. To review the summary, please use the following link:

http://www.cancer.gov/cancertopics/pdq/genetics/skin/HealthProfessional/Page4#Section_786

The PDQ Pediatric Cancer Treatment Editorial Board recently completed a major update of the Wilms Tumor and Other Childhood Kidney Tumors Treatment summary. The Board conducted a review of the published literature and revised the text of the summary and updated the citations.