AHRQ

RESEARCH IN ACTION

Agency for Healthcare Research and Quality • www.ahrq.gov

Issue #5 *May 2002*

Expanding Patient-Centered Care To Empower Patients and Assist Providers

Patients have more information today about their diseases and treatment options than ever before. But patients have not had tools to help them decide among these various options, and doctors have not had tools to help gauge how acceptable an option might be to a specific patient. As a result, the medical decision made, in hindsight, may not have been the most suitable one.

In the area of health plan enrollment, information to help patients make better decisions has not been made available. For example, when trying to decide about which health plan to join or provider to see, it would be useful to know about the experiences of others already enrolled in that plan or cared for by its providers, but that information has not been published widely. This, too, could result in patients making unsuitable decisions.

This report describes tools developed by the Agency for Healthcare Research and Quality that are currently available to help patients and their providers make better decisions. It suggests that a broader application of existing tools, as well as the development of similar tools for different areas of care, will improve the quality of care from the perspectives of patients, providers, and health plans. The tools described in this report include patient questionnaires for prostate symptoms and visual function, a consumer survey (Consumer Assessment of Health Plans Survey, or CAHPS®), and several publications on choosing health plans, obtaining quality care, avoiding medical errors, and getting preventive care.

Health care evolves toward a patient-centered model

Health care has been evolving away from a "disease-centered model" and toward a "patient-centered model." In the older, disease-centered model, physicians make almost all treatment decisions based largely on clinical experience and data from various medical tests. In a patient-centered model, patients become active participants in their own care and receive services designed to focus on their individual needs and preferences, in addition to advice and counsel from health professionals.

When patients and providers have a choice among treatment plans, a patient-centered approach has much to recommend it. This can happen when physicians do not agree on the optimal management for the condition or when different non-life-threatening outcomes may result from the different treatments available for a condition. Examples of such "preference-driven" conditions are benign enlargement of the prostate and visual problems resulting from cataracts. In such cases, the best treatment strategy depends on the strength of patients' preferences for the different health outcomes that may result from a treatment decision.[1]

Making a Difference

- **Almost all urologists use the prostate symptom index, and many have changed diagnosis and management strategies because of it…Page 2.**
- **Changes in visual function scores may be a better measure of the benefit of cataract surgery than changes in vision measured by using a standard eye chart…Page 3.**
- **Other information resources available to patients and providers can help in choosing health plans, avoiding medical errors, ensuring quality care and prevention services…Page 5.**

Questionnaires help determine treatment preferences

The shift toward patient-centered care has meant that a broader range of outcomes from the patient's perspective needs to be measured in order to understand the true benefits and risks of health care interventions. Tools developed as a result of AHRQ funding have helped patients with benign prostatic hyperplasia (BPH) and cataracts make important treatment decisions.

Prostate disease

Patients with prostate disease are gaining greater input into decisionmaking. Patient questionnaires to measure symptoms of prostate disease are examples of tools that give patients more input into their treatment while allowing providers to make more effective use of their practice time. AHRQ-funded research has resulted in a tool that allows patients to describe and providers to assess the impact of benign prostatic hyperplasia (BPH) symptoms experienced by the patient.[2] By considering the information provided by this tool, the physician is able to make a better informed treatment recommendation. Research has shown that this tool can help physicians describe, evaluate, and predict patient symptoms and treatment outcomes.

BPH is a very common condition, affecting more than 50 percent of men in their sixties and up to 90 percent of men in their seventies and eighties. It is a nonmalignant but progressive condition caused by prostate enlargement, which can lead to obstruction of the urethra and chronic urinary symptoms or infections. Prostatectomy—removal of the prostate—is performed on many men each year to treat this condition. Since BPH is rarely life threatening but can have considerable impact on a patient's quality of life, treatments are more preference driven than for conditions such as cancer.

Men who suffer symptoms from prostate enlargement have the following alternatives: "watchful waiting," medications, or prostatectomies (as well as other surgical interventions) to improve their health status. "Watchful waiting" is closely monitoring a patient's condition but not instituting therapy until symptoms appear or change. For patients uncertain about the necessity of surgery, watchful waiting and medications are alternatives. In selecting any of the above treatments, evaluating the symptoms from the patients' point of view has become increasingly important as a preliminary step.

Factors important to patients include how often symptoms occur and how severe the symptoms are.[3] In order to measure these factors, AHRQ-funded researchers have developed a patient questionnaire.

Most urologists use the symptom severity index. The questionnaire, developed in collaboration with the American Urological Association (AUA), incorporates a symptom index focusing on the severity of BPH symptoms as reported by the patient. Middle-aged or elderly men complaining of urinary difficulties and considered to have BPH are requested to fill out a questionnaire. Each of the seven questions included asks the patient to rank a particular symptom on a scale of 0 to 5, with 5 being the most severe. The symptoms are incomplete emptying, frequency, intermittency, urgency, weak urinary stream, hesitancy, and nocturia. (Questions are shown in Box 1.) Upon completion of the test, the numbers are added up in order to determine the overall severity of BPH-related symptoms. Based on these totals, the patient's symptoms are classified as mild, moderate, or severe.[4]

According to a survey of over 500 urologists, 99 percent were aware of and used the AUA symptom severity index, and 21 percent of those had altered their diagnosis and management strategies because of it.[5] Measures of symptoms and BPH-specific health status provide the most detailed and sensitive measures of treatment effectiveness from the patient's perspective, according to AHRQ-funded researchers.[3]

Other indexes for BPH have been developed. After the development of the AUA index, AHRQ-funded researchers developed two other questionnaires.[3] The symptom problem index (SPI) measures how bothered the patient is by BPH-related symptoms, and the BPH impact index (BII) measures how much a patient's urinary problems affect other areas of health. These measures could be more widely used for the clinical benefit of patients.

Box 1. American Urological Association symptom severity index for benign prostatic hyperplasia

1. Over the past month or so, how often have you had a sensation of not emptying your bladder completely after you finished urinating?
2. Over the past month or so, how often have you had to urinate again less than 2 hours after you finished urinating?
3. Over the past month or so, how often have you found you stopped and started again several times when you urinated?
4. Over the past month or so, how often have you found it difficult to postpone urination?
5. Over the past month or so, how often have you had a weak urinary stream?
6. Over the past month or so, how often have you had to push or strain to begin urination?
7. Over the last month, how many times did you usually get up to urinate from the time you went to bed at night until the time you got up in the morning?

For questions 1-6, there is a choice of six possible answers: never; less than one time in five; less than half the time; about half the time; more than half the time; almost always. Question 7 has six possible answers, ranging from zero to five or more.

Source: Wennberg JF. Prostate Disease Patient Outcomes Research Team (PORT) Final Report. Rockville (MD): Agency for Health Care Policy and Research; 1995. Publication No. PB95-253811.

The symptom index has also proved useful for prostate cancer patients treated with brachytherapy. In addition to being useful in the treatment of patients with BPH, the AUA prostate symptom index has been helpful when treating patients with prostate cancer who are undergoing brachytherapy. Brachytherapy is a form of radiation therapy in which tiny radioactive pellets are implanted into the prostate in order to treat patients diagnosed with prostate cancer. In one study, nurses monitored patients' health status after surgery and discharge from the hospital by conducting periodic telephone interviews that included the symptom index.[6] Depending on the patient's response to the index's questions, the dosage levels of his medications were adjusted or further tests recommended. The researchers recommend that nurses use the symptom index when they care for patients treated with brachytherapy.

Cataract

Patients' everyday visual function is linked closely to their satisfaction with cataract surgery outcomes. The Visual Function-14 Index (VF-14) is a tool that helps patients and physicians assess the need for and the outcome of cataract surgery. It acts as a supplement to the standard eye chart (a key clinical test for vision) and other clinical measures.

Cataracts, the clouding of the eye's lens, can cause vision problems and are usually related to aging. At least 50 percent of all Americans age 65 and over have a cataract.[7] To correct this condition, about 1.3 million cataract extractions are performed on Medicare beneficiaries in the United States each year.[7] It is the most frequently performed operation for Medicare patients.[8]

AHRQ-funded researchers developed the VF-14 to measure patients' experience—how well patients with cataract disease were able to pursue their usual activities. Specifically, the VF-14 measures the amount of difficulty patients have in performing 14 vision-dependent everyday activities, such as driving and reading small print. The specific activities are shown in Box 2.

To test the value of the VF-14, AHRQ-funded researchers administered it to 775 pre-operative cataract patients along with several tests of visual acuity and the Sickness Impact Profile (SIP), a behavior-based measure of general health status. The results showed that the VF-14 scores correlated

Box 2. Functional activities included in Visual Function-14 Index

The VF-14 measures everyday functioning in 14 areas:

- **Reading small print (e.g., prescription labels).**
- **Reading a newspaper or book.**
- **Reading a large-print book or numbers on a phone.**
- **Recognizing people nearby.**
- **Seeing steps, stairs, or curbs.**
- **Reading traffic, store, or street signs.**
- **Doing fine handiwork (e.g., sewing).**
- **Writing checks or filling out forms.**
- **Playing games (e.g., cards, bingo).**
- **Playing sports (e.g., golf, bowling).**
- **Cooking.**
- **Watching television.**
- **Driving during the day.**
- **Driving at night.**

Each item on the index was assigned a score, depending on the amount of difficulty the patient reported: 4 for "no difficulty" with the activity, 3 for "a little," 2 for "a moderate amount," and 1 for "a great deal" of difficulty. A score of zero was assigned when the patient was "unable to do" the activity because of his or her vision. Items were not included in scoring if the patient did not perform the activity for a reason other than vision.

Source: Steinberg E, Tielsch JM, Schein OD, et al. The VF-14 as an index of functional impairment in cataract patients. Arch Ophthalmol 1994; 112:630-8.

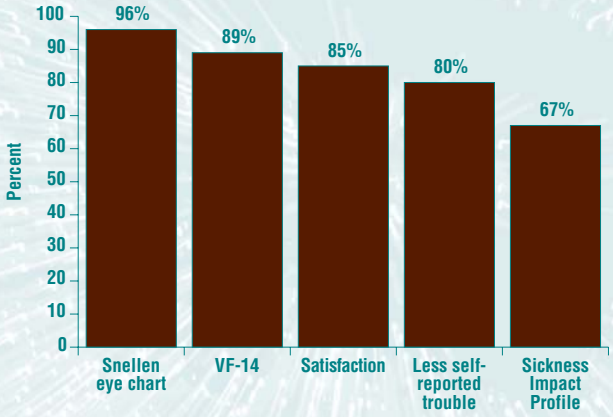
more strongly with the overall self-rating of the amount of trouble and satisfaction patients had with their vision than did several measures of visual acuity or the SIP score.[8]

A related AHRQ-funded study looked at 552 post-operative patients 4 months after their cataract surgery.[9] The percentage of patients who were rated as having improved 4 months after surgery depended on which outcome measure was used: 96 percent had improved visual acuity as measured on a standard eye chart; 89 percent had an improved VF-14 score; 85 percent had improved satisfaction with vision; 80 percent had less self-reported trouble with vision; and 67 percent reported improvement based on the general health status test (SIP).[9] (See Figure 1.) As with the earlier study of preoperative cataract patients, the patients' ratings of their trouble and their satisfaction with vision correlated more strongly with the VF-14 score than with the change in their ability to read a standard eye chart.

To assess the relative importance of patient preferences and the results of standard eye chart tests, another AHRQ-funded study interviewed patients over age 50 who were scheduled to have routine cataract extraction within 3 months for an age-related cataract. Using several tests, the patients were asked to rate the effects of visual impairment on specific aspects of their daily lives, including work, leisure activities, walking, driving, social interactions, concentration, memory, and feelings. They were then asked to rate their current vision on a scale ranging from 0 for complete blindness to 10 for perfect vision.[10]

The researchers found that patients' level of satisfaction with their vision before surgery was more closely related to problems in specific aspects of daily life—especially feelings of depression and problems in social interaction—than to visual acuity as measured by the standard eye chart. For example, more than 60 percent of patients reported frustration with visual impairment, and more than 25

Figure 1. Percentage of patients reporting improvement after cataract surgery based on 5 measures



Note: VF-14 is the Visual Function-14 Index.

Source: Steinberg E, Tielsch JM, Schein OD, et al. National Study of Cataract Surgery Outcomes. Ophthalmology 1994; 101:1131-9.

percent reported that their current vision caused problems with driving, leisure activities, walking, and working.[10]

Many insurers (including Medicare) now require that the results of the VF-14 be reported as a condition of claims payment, and it has been adapted for use in at least a dozen other countries. This measure is also required in all clinical trials sponsored by the National Eye Institute to test the benefits of new technologies and procedures for cataract patients.

The VF-14 can be used with other eye problems besides cataract, such as retinal disease and corneal grafts. For example, in a study of corneal graft patients, researchers found that the VF-14 accurately measured visual impairment. They reached their conclusion after comparing it with other measures of vision problems.[11]

Information on consumer choices empowers patients

In addition to helping patients make better treatment decisions, AHRQ also sponsors research and provides information resources so that consumers may make better informed choices when they select health plans and health care providers and in their overall use of medical care. Information is available from AHRQ on such topics as:

- Helping consumers choose health plans and get good care from their doctor.
- Avoiding medical errors.
- Making sure they get proper preventive care.

CAHPS®

AHRQ's consumer survey, CAHPS®, helps patients choose health plans and obtain good health care. Consumers can now access comparative information about health plans based on other consumers' experience with the health care they received from plans and providers. This information is available through CAHPS®, a survey sponsored and funded by AHRQ and its partner, the Centers for Medicare & Medicaid Services (CMS). CAHPS® results help inform consumers about their choices among health care plans. They also allow health plans, employers, and others to obtain consumers' views of the care they are receiving. The surveys are in the public domain and available free of charge.

Many public and private entities use CAHPS® results to make decisions about which plans to contract with or make the findings available to their beneficiaries or employees so they can decide which plan to enroll in. These entities include more than 20 State Medicaid programs, 10 employer groups, the Medicare program, the Federal Employees Health Benefits Program, the Department of Defense, health plans surveyed by the National Committee for Quality Assurance, and a division of Ford Motor Company. In 1999, over 90 million Americans received information on health plans resulting from CAHPS®.[12]

CAHPS® questionnaires are typically mailed to consumers by the sponsoring organization (e.g., the Medicare program, State health departments, and individual health plans). Consumers are asked about satisfaction with:

- Getting needed care.
- Getting care quickly.
- How well doctors communicate.
- Courtesy and helpfulness of office staff.
- Customer service.

They are also asked to rate:

- Their physicians.
- Their health care.
- Their health plan.

After tabulation, results are presented, often in a report-card format that shows how satisfied consumers are with specific aspects of health plan and provider performance. These reports are made available to those making enrollment decisions.

CAHPS® can be used to collect information about enrollees' experiences with all types of health insurance programs (Medicaid and Medicare beneficiaries as well as the privately insured) and across the full range of health care delivery systems, from fee-for-service to managed care plans. Separate questions are designed to capture the experiences of certain subgroups, such as people with chronic conditions or disabilities, Medicaid and Medicare beneficiaries, and families with children. This is especially important because people in these groups may need different types of information.[13]

CAHPS® is expanding its range. To assist patients in choosing a specific doctor or group practice, the CAHPS® team has developed a CAHPS® survey for group practices and is examining the feasibility of a CAHPS® survey for individual providers.

Other tools to help consumers choose quality care

Consumers want and need more tools to help them decide about which health plan or doctor is best for them. To meet this need, AHRQ has developed, printed, and made available on its Web site two documents: *Choosing and Using a Health Plan* (AHCPR Publication No. 97-0011, available on the Web at http://www.ahrq.gov/consumer/hlthpln1.htm) and *Be Informed: Questions To Ask Your Doctor Before You Have Surgery* (AHCPR Publication No. 95-0027, available on the Web at http://www.ahrq.gov/consumer/surgery.htm).

Both documents focus on questions that patients need to ask in order to ensure that they select physicians appropriate for them. For example, there are specific questions about:

- What services the plan covers.
- How well the doctor communicates.
- What hospitals the doctor uses.
- The risks and benefits of surgery.
- Alternatives to surgery.

Information to help avoid medical errors

Sizable numbers of Americans are harmed each year as a result of medical errors, according to an a report by the Institute of Medicine.[14] Although those working at different levels of the health care system are primarily responsible for changing the systems that contribute to these errors, patients can take actions that might help them avoid experiencing an adverse event.

AHRQ has published a patient fact sheet, *20 Tips to Help Prevent Medical Errors* (AHRQ Publication No. 00-P038, available on the Web at http://www.ahrq.gov/consumer/20tips.htm). The tips focus on communication between the provider and the patient. They help patients make sure that they have both given the physician all the information that he or she may need and also elicited for themselves all the relevant information they might need to understand their condition and treatment options. Although using all 20 tips would be helpful, AHRQ also has published an abbreviated list, *Five Steps to Safer Health Care* (Publication No. OM 00-0004, available on the Web at http://www.ahrq.gov/consumer/5steps.htm), that has appeared in many consumer publications. These steps are—

- Speak up if you have questions or concerns.
- Keep a list of all medications you take.
- Make sure you get the results of any test or procedure.
- Talk with your doctor and health care team about your options if you need hospital care.
- Make sure you understand what will happen if you need surgery.

Information on preventive care

AHRQ sponsors Put Prevention Into Practice (PPIP), a program whose goal is to preserve the health of all Americans by increasing the appropriate use of clinical

AHRQ-Funded Research on Patient-Centered Care

***Prostate Disease Patient Outcomes Research Team*, 1989-94. Dartmouth Medical School. Developed standardized measurements of the symptom burden and health status impact of benign prostatic hyperplasia and early-stage prostate cancer. Developed understanding of critical role of patient preferences for men with prostate disease.**

***Variations in Cataract Management: Patient and Economic Outcomes*, 1989-95. The Johns Hopkins University. Documented variation in clinical outcomes, patient functioning, patient satisfaction, and health care costs as a function of alternative strategies for cataract management. Determined the values patients and ophthalmologists place on specific potential clinical and functional outcomes of cataract management.**

***CAHPS® (Consumer Assessment of Health Plans Survey),* 1995-2000. Harvard University, RAND, Research Triangle Institute. Developed and tested an easy-to-use kit of survey and report tools that provides reliable and valid information to help consumers and purchasers assess and choose among health plans. The kit contains a set of questionnaires to ask consumers about their experience with their health plans, sample formats for reporting results to consumers, and a handbook to help implement the surveys and produce the reports.**

preventive services, such as screening tests, immunizations, chemoprevention, and counseling. Based on the recommendations of the U.S. Preventive Services Task Force, PPIP is a national initiative working in partnership with public and private health care organizations.

PPIP improves the delivery of preventive services and helps facilitate communication between health care providers and patients. Tools and resources inform clinicians about recommended clinical preventive services in primary health care and inform the public about the individual's role in staying healthy. PPIP materials are based on scientific information and on evaluation by users. All materials are evidence based and promote a team approach to the delivery of preventive services. They are designed for health care systems and clinicians, the office/clinic staff, and health care consumers.

Pocket-sized booklets for the general public, including the *Personal Health Guide, Child Health Guide,* and *Staying Healthy at 50+*, are available in English and Spanish. (AHRQ Pub. No. APPIP 01-0009, including the three PPIP patient booklets, is available on the Web at <http://www.ahrq.gov/clinic/ppipix.htm>.)

These guides provide tips and recommendations for children, adults, and adults age 50 and over on health habits, screening tests, and immunizations. They encourage patients to actively participate in their preventive care and include easy-to-use charts to help track personal health information.

The *Clinician's Handbook of Preventive Services*, 2nd Edition, is both a reference tool and a practical guide to delivering clinical preventive services in a variety of settings.[15] *A Step-by-Step Guide to Delivering Clinical Preventive Services: A Systems Approach* is an implementation guide for health care systems.[16] Other materials, including preventive care flow sheets, reminder postcards, and prevention timeline posters, are designed for clinical office staff.

For more information on how PPIP tools have been used, go to <http://www.ahrq.gov/ppip/ppipcase.htm>.

AHRQ publications are available from the AHRQ Clearinghouse at 1-800-358-9295.

Research continues

AHRQ is continuing its efforts to fund research that advances patient-centered care.

AHRQ's program announcement "Patient-Centered Care: Customizing Care to Meet Patients' Needs" is intended to support the redesign and evaluation of new care processes that lead to greater patient empowerment, improved patient-provider interaction, easier navigation through health care systems, and improved access, quality, and outcomes.[17]

Examples of specific strategies include electronic clinical communication, self-management programs, Web-based applications for patients and/or health care providers, and shared decisionmaking programs. AHRQ encourages projects that emphasize chronic illness, episodes of care that extend beyond hospitalization, longitudinal care, and priority populations. For more information, see the AHRQ Web site at <http://grants1.nih.gov/grants/guide/pa-files/PA-01-124.html>.

AHRQ funds are also being used to define the current pattern of screening, diagnosis, and treatment of prostate disease among primary care physicians and urologists.

Conclusion

AHRQ-funded research has developed patient-reported functional status indicators that empower patients and assist providers in achieving desired outcomes. Consumers also benefit from CAHPS® survey findings and other information resources that are available to the public in a variety of media.

Working together, providers and researchers can identify new areas where such tools need to be developed, find ways to test them in clinical settings, and implement them broadly. By so doing, the health care system can come much closer to realizing the goals of patient-centered care.

For more information

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**** AHRQ-funded/sponsored research***

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1	Reducing and Preventing Adverse Drug Events To Decrease Hospital Costs	AHRQ 01-0020

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Health and Human Services

Public Health Service
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AHRQ Pub. No. 02-0024
May 2002