

## Information about tests for breast cancer: What are we telling people?

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We reviewed publications currently available about breast cancer screening to assess what information was provided about test accuracy and pretest and posttest disease probabilities, as this information is needed by consumers to make informed decisions about whether to undergo testing and to fully understand test results. A rating form was developed and used to assess 54 publications about their reports of breast cancer tests. A description of how the test is done was provided by almost all publications (93%). About half (48%) provided some information about possible adverse effects of the test. Eighteen percent of publications provided some (generally qualitative) information about test accuracy, and none provided quantitative information about the probability of disease given normal and abnormal test results.

■ **KEY WORDS** Patient education; sensitivity and specificity; diagnosis; consumer participation; probability. (*J Fam Pract* 2002; 51:858-860)

It has been well established that patients want to participate in decisions about their treatment options<sup>1-3</sup>; therefore, they most likely also wish to participate in decisions about whether to undergo common diagnostic tests. A literature review (using the MESH headings *Patient education, Consumer participation, and Sensitivity and Specificity*) revealed only 1 study of patient knowledge and understanding of test accuracy for routine diagnostic tests.<sup>4</sup> This study found that patients knew little about disease probabilities and diagnostic test characteristics, even if they had previous experience with the target disease. Some studies have addressed the information that people should be given about screening tests,<sup>5-8</sup> and guidelines from the General Medical Council of the United Kingdom specify that information about the likelihood of positive or negative findings including false-negative and false-positive results must be provided.<sup>9</sup> Logically, similar information should be available to individuals undergoing common diagnostic tests, but to our knowledge, no systematic assessment of the information available to consumers about common tests has been conducted. We therefore set out to

assess the information provided about common tests in current consumer publications. Given the findings of the previous study,<sup>4</sup> we were particularly interested to see whether information about test accuracy and about pretest and posttest probabilities was provided. We assessed breast cancer screening and diagnostic tests because much has been written for the public about breast cancer tests, and the information provided is usually relatively sophisticated.

### METHODS

#### The Rating Form

We developed a rating form to record the type of information in each publication. Following the recommendation that consumers' questions should drive the content of information,<sup>3</sup> we used "Questions to ask your physician about tests" in *Smart Health Choices*, a consumer-oriented book about making health decisions,<sup>10</sup> and the General Medical Council guideline for providing information about screening tests<sup>9</sup> to develop the rating form. In addition to assessing information about false-positive and false-negative results (test accuracy), pretest probabilities and posttest probabilities given a normal or abnormal test result, we assessed whether information was given about how the test is conducted, likely emotional responses to being tested, and shared clinical decision making. The rating form consisted of 16 items (see Table W1, available at <http://www.jfponline.com>). A 5-point Likert scale was used to rate the publications on each item from 1 (no information) to 5 (detailed information).

#### The Publications

In December 1999 and January 2000 we telephoned the New South Wales (NSW) Cancer Council (the leading cancer advocacy center in NSW), the NSW BreastScreen Coordinating Unit (which coordinates

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all government-funded breast screening and assessment services in NSW, operating from 36 clinics) and 2 large private breast clinics. We also phoned the larger BreastScreen clinics directly. We asked for all pamphlets, booklets, or other written patient education materials about breast tests. Publications were received from 12 locations of 14 telephoned, (86%).

### Rating Agreement

We chose 10 publications at random and 2 of us (A.B. and P.B.) rated them independently. Overall, there was perfect agreement for 79% of the items, near agreement (1 point difference on the Likert scale) on 12% of items, and more than 1 point difference on the Likert scale on the remaining 9% of items. Based on these results we modified the scale slightly to reduce ambiguity and clarified how to rate information in a written guide. One of us (E.C.) rated all 54 publications using the guide and the rating form.

## RESULTS

We received 54 publications. Of these, 43% contained information on breast self-examination, 51% clinical examination, 69% screening mammography, 44% diagnostic mammography, 30% diagnostic ultrasound, 30% fine-needle aspiration biopsy, 28% core biopsy, 13% open surgical biopsy, and 7% genetic testing. The publications were written by cancer organisations, the BreastScreen Coordinating Unit, and by individual public and private clinics. Most were brief (1–4 A4 pages) although 1, on all aspects of breast cancer detection and treatment, was 44 pages long.

Almost all publications described how the test is done and half provided information about possible adverse effects of tests (Table). Only a minority of publications provided specific information about pretest probability (eg, how breast cancer risk changes with age), test accuracy, or posttest probability (Table). Where breast cancer risk was mentioned it was usually given in the form of a lifetime risk of a woman developing breast cancer. However, 13% of publications provided information about the risk of developing breast cancer in the next 5 to 10 years and one gave age-specific risks. Information about test accuracy was given as “not all cancers are detected” by the test (9%) or “9 out of 10 cancers are detected” by the test (7%). Quantitative estimates of

**TABLE**

### Percentage of 54 patient education publications rated as providing information on key items about breast cancer screening

| Information about  | Publications providing any information (rating 2-5) | Publications providing substantial information (rating 4 or 5) |
|--|---|--|
| How the test is done (%)   | 93  | 57   |
| How breast cancer risk varies by age (%)                         | 37  | 15   |
| Adverse effects of tests (%)                                     | 48  | 9  |
| Test accuracy, ie, false-positive and false-negative results (%) | 18  | 2  |
| Posttest probability given a normal or abnormal test result (%)  | 20  | 0  |

specificity and positive predictive value were provided in 1 publication. Information about the probability of disease given a positive test result was given as “About 1 in 20 women are asked to come back for further tests. 9 out of 10 women who are recalled do not have breast cancer” in a few publications. Information about posttest probability given a normal test result was not given in any publication. Results of ratings on other items are available directly from the corresponding author.

## DISCUSSION

We found that the quantitative information women need to make informed choices about whether to undergo a breast cancer screening and to fully understand the test results was lacking in most publications. The most commonly used format for expressing the prior probability of breast cancer was lifetime risk; age-specific information was rarely provided. As the risk of breast cancer varies greatly with age, age-specific prior probabilities, not lifetime risk, are needed for informed decision making. Few publications provided information about test accuracy. Failure to acknowledge that tests may give false-positive and false-negative results may mislead people in interpreting their results. For example, people may think that if the test is negative, disease is absent, whereas in reality a negative test reduces but does not eliminate the possibility of disease. Conversely, many tests give positive (or abnormal) results, which prompt anxiety even though disease is absent. In the absence of information about test accuracy it is likely that misconceptions about test results will persist.

Some limitations of the study should be noted. Although publications commonly used in New South Wales (the most populous state of Australia with approximately one third of the total national popu-

lation) are unlikely to have been missed in this study, we cannot guarantee that all publications currently in use were obtained. Secondly, we acknowledge that the ratings may have been different if others rated these publications. However, it is unlikely that either of these considerations is substantial enough to affect the general direction of the findings.

In conclusion, we suggest that there is an urgent need to ascertain what information consumers need about screening and diagnostic tests so they can make rational, informed choices. Communicating information about pretest probability, test accuracy, and posttest probability to consumers will require careful development and evaluation work. However, this work is essential so that people can give truly informed consent to being tested. Further, good information is needed for those people who want to participate actively in decisions about whether to undergo a test, and to support more accurate patient understanding of test results.

#### REFERENCES

1. Degner LF, Kristjanson LJ, Bowman D, et al. Information needs and decisional preferences in women with breast cancer. *JAMA* 1997; 277:1485-92.
2. Coulter A. Evidence based patient information is important, so there needs to be a national strategy to ensure it. *BMJ* 1998; 317:225-6.
3. Coulter A, Entwistle V, Gilbert D. Sharing decisions with patients: is the information good enough? *BMJ* 1999; 318:318-22.
4. Hamm RM, Smith SL. The accuracy of patients' judgements of disease probability and test sensitivity and specificity. *J Fam Pract* 1998; 47:44-52.
5. Wolf AM, Becker DM. Cancer screening and informed patient discussions: truth and consequences. *Arch Intern Med* 1996; 156:1069-72.
6. Raffle AE. Information about screening—is it to achieve high uptake or to ensure informed choice? *Health Expect* 2001; 4:92-8.
7. Goyder E, Barratt A, Irwig LM. Telling people about screening programmes and screening test results: how can we do it better? *J Med Screen* 2000; 7:123-6.
8. Marteau TM, Saidi G, Goodburn S, Lawton J, Michie S, Bobrow M. Numbers or words? A randomized controlled trial of presenting screen negative results to pregnant women. *Prenat Diagn* 2000; 20:714-8.
9. General Medical Council. Seeking Patients' Consent: The Ethical Considerations. London, UK: General Medical Council; 1999.
10. Irwig J, Irwig L, Sweet M. Smart Health Choices: How to Make Informed Health Decisions. Sydney, Australia: Allen & Unwin; 1999.

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