ORIGINAL RESEARCH

The Accuracy of Patients' Judgments of Disease Probability and Test Sensitivity and Specificity

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BACKGROUND. We studied patients' understanding of the characteristics of diagnostic tests for six common conditions to determine what patients know about diagnostic uncertainties before they communicate with a doctor. We compared the accuracy of patients' estimates of disease probabilities and diagnostic test characteristics for diseases with which they did or did not have prior experience.

METHODS. To measure patients' understanding of the uncertainty of diagnostic test results, questionnaires describing diseases were given to patients in clinic waiting rooms. For each of six diseases, a 2-page questionnaire presented a case history of the disease and its diagnostic test, and asked respondents to estimate the probability that the case patient has the suspected disease, the sensitivity of test, the specificity of test, and the probability that the patient has the disease if the test result is positive. It also asked whether the patient, a close friend, or family member had ever been thought to have this disease.

RESULTS. One hundred eighty-four patients in the clinic waiting room responded for at least one disease. Although patients judged the disease probabilities to be higher after a positive diagnostic test, each of their four judgments was essentially the same for all diseases, including those with high and low prior probabilities, and with accurate and inaccurate tests. Past experience with the disease was associated with only a minimal increase in the accuracy of patient knowledge.

CONCLUSIONS. Patients' ignorance of the uncertainties of diseases demonstrates the need for patient education when a disease is suspected. The lack of relation between knowledge and experience suggests that this need is not being effectively met. To convey the rates or probabilities, and to help the patients understand what the probabilities are based on, a physician should speak in terms that patients can easily understand.

KEY WORDS. Probability; physician-patient relations; patient education; diagnosis; sensitivity and specificity. *(J Fam Pract 1998; 47:44-52)*

Diagnostic uncertainty creates uncertainty about treatment and prognosis. Physicians have adopted a variety of approaches for discussing these uncertainties with patients, ranging from providing explicit numerical or verbal probabilities to denying the uncertainty,[1] and patients have expressed various preferences as to how their physicians should address these uncertainties.[2-6]

Physicians generally endorse the need for informed consent and truth-telling with regard to diagnostic uncertainty.[7] Many would discuss probabilities (ie, prevalences of disease, probability the patient has a disease given the clinical presentation, sensitivity and specificity of a test, probability the patient has a disease after a positive or a negative test result) if they believed the probabilities were well-founded and patients would understand them. It is not known, however, whether patients understand information about diagnostic uncertainties, presented in terms of probabilities. It is possible that the presentation format confuses patients.[8] For these reasons, it is not clear which is the most effective way to talk with patients about diagnostic uncertainty.

Patient interpretations of diagnostic uncertainty have rarely been studied. For example, the concept was not mentioned in a recent review of physician-patient communication.[9] To find out what patients know concerning diagnostic uncertainties before they communicate with a doctor, we studied their understanding of the characteristics of diagnostic tests for six common conditions. Our study sought to describe what patients know, before talking with their physicians, about the test characteristics of diagnostic procedures that may be applied when a disease is suspected.

METHODS

Procedure

Patients waiting in primary care clinics during a 2-week period early in 1994 were asked to fill out questionnaires

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each containing a vignette (Figure 1) describing a patient "such as yourself" who presented with a problem that suggested a disease (eg, small bowel obstruction) and received a diagnostic test (eg, abdominal radiograph). Questionnaires were prepared for six different diseases, selected for their varying test characteristics.[10-16]

The study was done in two clinics. In a Colorado clinic serving both active-duty and retired army personnel and their families, patients were approached at the convenience of clinic staff and each patient was given all 6 questionnaires. In an Oklahoma clinic serving primarily a low-income urban population, each patient was given only one questionnaire, and it was handed out along with a patient satisfaction evaluation sheet. Although the staff tried to get all patients to respond, the clinic had placed a priority on the patient satisfaction form. Assignment of the particular disease vignette to each patient was random because the stack of questionnaires was shuffled. No information is available about the proportion of patients in either clinic who refused to participate or were unable to complete the questionnaire.

Using nontechnical language, the patient was asked to judge the probability of disease before the diagnostic test, test sensitivity and specificity, and the disease probability if the test result is positive. Response choices consisted of 13 percentages ranging on a scale of 0% to 100%, with the intervals more closely spaced near the extremes (Figure 1). The questions asked how many of 100 people would have the specified outcome, because we expected patients might have difficulty understanding a question about "probability."[17]

VIGNETTES

Six vignettes were prepared: small bowel obstruction, pulmonary embolus, strep throat infections, HIV, herniated lumbar disk, and acute myocardial infarction. The set included both common and uncommon diseases. The sensitivity and specificity of their standard diagnostic tests vary from about .50 to .99 (Table 1). Three physicians reviewed the vignettes for realism.

Patients were asked their age, sex, and experience with the disease (ie, whether they had ever had a test

FIGURE 1

An example of a questionnaire used to determine patients' judgment of disease probability: small bowel obstruction vignette.

A person such as yourself might experience abdominal pain, a distended abdomen, constipation, and vomiting. It would be natural for the patient to go to the doctor's office because he is worried about these symptoms. The doctor might suspect the patient has an obstruction of the small bowel, a condition that needs a surgical operation if it does not get better on its own soon. To check whether a patient has a small bowel obstruction, the doctor might have the patient undergo an X-ray of the abdominal region, a procedure that takes some time and costs a moderate amount, and involves exposing the patient to a small amount of radiation.

The following questions ask you how common small bowel obstructions are and how accurate the abdominal X-ray is in determining whether a person has a small bowel obstruction. Answer to the best of your knowledge. Read the question over if you are not sure.

1. Let's think about 100 people with abdominal pain, a distended abdomen, constipation, and vomiting, who the doctor suspects might have a small bowel obstruction. How many of these people would actually have a small bowel obstruction?

0% 2% 5% 10% 20% 35% 50% 65% 80% 90% 95% 98% 100%

2. Now let's think about 100 people who actually have a small bowel obstruction, and whose doctor gets them an abdominal X-ray. How many of these people would the X-ray say have a small bowel obstruction?

0% 2% 5% 10% 20% 35% 50% 65% 80% 90% 95% 98% 100%

3. Next, consider 100 people who have the symptoms described, but NOT due to an obstruction of the small bowel. For how many of these people would the abdominal X-ray say, correctly, that they DO NOT have a small bowel obstruction?

0% 2% 5% 10% 20% 35% 50% 65% 80% 90% 95% 98% 100%

4. Finally, consider 100 people who have the symptoms described and their abdominal X-ray says that they have a small bowel obstruction. How many of these people would really have a small bowel obstruction?

0% 2% 5% 10% 20% 35% 50% 65% 80% 90% 95% 98% 100%

TABLE 1

Diagnostic Probabilities (Test Characteristics and Pretest Disease Probabilities) for the Six Disease Vignettes, Compared with Mean Patient Estimates

Disease	Test	Probability Before Test*	Patients' Mean Estimated Probability Before Test No. (SD)	Test Sensitivity Standard* No. (SD)	Patients' Mean Estimated Test Sensitivity No. (SD)	Test Specificity Standard*	Patients' Mean Estimated Test Specificity No. (SD)
Small bowel obstruction	Abdominal x-ray film[10]	.075	.50 47 (.31)	1.0	.78 47 (.31)	.90	.73 47 (.33)
Pulmonary embolus	Arterial PO2[11,12]	.125	.41 52 (.27)	.95	.66 51 (.31)	.50	.70 52 (.29)
Streptococcal infection	Throat culture[13]	.11	.37 49 (.25)	.90	.71 49 (.29)	.99	.69 48 (.36)
Human immuno-deficiency virus	ELISA blood test[14]	.085	.39 53 (.31)	.9898	.70 53 (.32)	.99	.71 52 (.32)
Herniated lumbar disk	CT scan[15]	.05	.41 50 (.26)	.97	.77 50 (.29)	.64	.79 50 (.28)
Acute myocardial infarction	ECG[16]	.21	.39 55 (.22)	.57	.76 54 (.30)	.98	.74 54 (.32)

*Mean of three physicians' estimates.
No. denotes the number of people the average is based on; SD, standard deviation.

for the disease and, if yes, whether they had been treated for it; whether they had ever attended an office visit with a member of their family or with a friend who was tested for the disease and, if yes, whether that person was treated for the disease.) We omitted questions about personal experience with HIV tests to respect patients' privacy.

ANALYSIS

The accuracy of patients' judgments was evaluated according to objective criteria. The sensitivity and specificity of each test were derived from pre-1994 research.[10-16] The standard for the probability of disease on presentation, before the test, was the mean of three primary care physicians' judgments based on the case description. The probability of disease when there was a positive test result was derived by applying Bayes' theorem to the prior probability, judged by the physicians, and the sensitivity and specificity found in the medical literature.[18] In the formula below, "P(Disease)" denotes the probability the patient has the disease, before a test, and "P(Disease/Positive Test)" denotes the disease probability after a positive test result.

$$P(\text{Disease/Positive Test}) = \frac{P(\text{Disease})*\text{Sensitivity}}{P(\text{Disease})*\text{Sensitivity} + (1-P(\text{Disease}))*(1-\text{Specificity})}$$

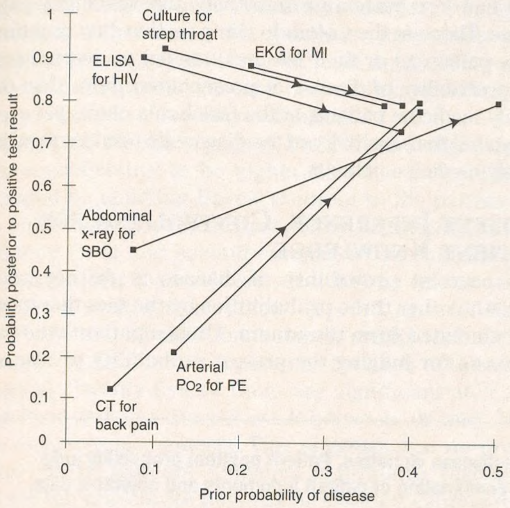
Two additional estimates of the probability of disease after a positive test result were calculated. The first adjusted the patient's own estimates of the disease's pretest probability using the patient's judgments of the test's sensitivity and specificity; the other adjusted the patient's estimate of pretest disease probability using the sensitivity and specificity figures reported in the literature.[19]

To measure patient accuracy, we used the absolute value of the difference between the patient's judgment and the criterion probability. Patient experience with each disease was measured by summing the number of yes answers to the questions about whether the patient or a friend or family member had been tested or treated for the disease.

Patients' probability estimates for each vignette were compared with the criterion answer using *t* tests. Comparisons between vignettes, and comparisons between accuracy and other variables (such as patient sex and experience), were complicated by the fact that patients at the retiree clinic read all the vignettes, while

FIGURE 2

Comparison of patients' estimates of disease probability with objective estimates, before and after a positive diagnostic test result.



Lines connect the objective probability estimates to the mean patient estimates for each disease. The tail of each line represents the objective probability of the disease before (*X* axis) and after (*Y* axis) a positive test result. The point at the head of the arrow represents the mean of the patients' judgments of those probabilities.

patients at the other clinic read only one. Although we did separate analyses for each clinic, we report statistics only from one-way and multi-way ANOVAs that assume all responses were from different people. The simplifying assumption of this model might be expected to overestimate the statistical significance of comparisons between vignettes. Alternative statistical tests that do not inaccurately assume those responses are independent were used for every comparison, but for simplicity these were not reported when the results were similar.

RESULTS

A total of 184 patients responded; 145 in the Oklahoma clinic who completed 1 questionnaire each, and 39 in the Colorado clinic who completed 1 to 6 questionnaires each (mean and median 4.9). It is not known how many patients declined to participate, or failed to complete and return the questionnaires. There were between 55 and 60 responses to each of the 6 vignettes. Of the 336 completed questionnaires, 175 were done by men, 160 by women, and one did not indicate the sex of the respondent. Ages ranged from 6 to 89 years (mean 48.7). The three children younger than 15 were assumed to be assisted by parents, whose age is not known.

Accuracy of Patients' Judgments of Disease Probability and Test Characteristics

Patients' mean estimates are given in Tables 1 and 2. Their judged probabilities after the positive diagnostic test result are substantially higher than before the test for all diseases (all *t* tests significant at $P < .001$), which is appropriate. However, comparison with the objective data shows that the patients' judgments are inaccurate.

More important, patients made the same judgments for all diseases. This is true for pretest (one-way ANOVA: $F_{5,265} = 0.84$, $P = .53$) and post-positive test result (ANOVA: $F_{5,265} = 0.33$, $P = .90$) judgments of the probability of the disease. An illustration of these results is given in Figure 2, showing an arrow for each of the disease vignettes. The arrow goes from a point indicating the objective pretest and posttest probabilities, to a point representing the patients' judgments of those probabilities. For example, the tail of the "CT for Back Pain" arrow indicates that the experts' judgment of the pretest probability is .05 and the calculated probability after a positive test is .12, while the opposite end indicates that patients on average thought the prior probability to be .41, and the probability after a positive CT scan result to be .80. While the objective probabilities (the tails of the six arrows) vary widely, the patients' judgments (the forward ends) are clustered together. This indicates that patients make no distinctions among the diseases when estimating their likelihoods, both before and after a positive test result.

Although the diagnostic tests for the six disease vignettes have very different characteristics, there were no differences between vignettes in patients' sensitivity judgments (ANOVA: $F_{5,265} = 1.67$; $P = .15$) or specificity judgments (ANOVA: $F_{5,265} = 0.81$; $P = .54$). In addition, the patients judged test specificity to be no different from test sensitivity (each of the six within-vignette *t* tests was nonsignificant).

Patient Experience with Disease and Accuracy

Patients with more experience made judgments that were more accurate (or less inaccurate), as indicated by a test for linear trend (on number of answers indicating experience with the disease) within a 1-way ANOVA, for the judgments of specificity ($F_{1,297} = 7.07$, $P = .008$) and of disease probability given a positive test result ($F_{1,299} = 5.33$, $P = .02$). However, the judgments made by patients with experience of the disease were still quite inaccurate. Experience had no effect on the accuracy of the sensitivity judgments ($F_{1,300} = 0.03$, $P = .87$) or the pretest probabilities ($F_{1,301} = 0.47$, $P = .49$). This analysis treats all questionnaires as independent, although patients at one clinic completed multiple questionnaires. Analyses of the data from the two clinics separately, using appropriate models for each clinic, showed the same results at the Oklahoma clinic but no relation to experience at the Colorado clinic. Thus, there is only weak and inconsistent evidence that patients who have experience with a disease have better knowledge of the uncertainty of that disease and its diagnostic test.

Patient Demographic Factors and Accuracy

The accuracy of the patients' judgments was related (in multiple regression analyses) to some demographic factors. We mention only the statistically significant relations that were found both in analyses of all patients together and in analyses that looked at each clinic separately. (Details of these comparisons are available from R.M.H. on request.) Older respondents' sensitivity and specificity judgments were less inaccurate. This also held when the respondents younger than 16 were excluded from the analysis. The relation to age was independent of the relation to disease experience. Exploration of alternative models excluding and including age as a predictor eliminated the possibility that age might have somehow masked, or accounted for, the impact of experience with the disease. Men had less inaccurate sensitivity and specificity judgments. Those at the Colorado clinic (active duty or retired army personnel or their families) tended to overestimate the probability of disease at presentation more than the family medicine patients at the Oklahoma clinic, yet overestimated the sensitivity of the diagnostic test less than the family medicine patients.

Patient Inference, Controlling for Patient Knowledge

The posttest probability of disease is distinguished from the other three probabilities by the fact that it can be calculated from the others. Thus, a patient who has no basis for judging the pretest probability of disease

TABLE 2

Estimates of disease probabilities given a positive test result, for the six disease vignettes. Patient posttest probability judgment compared with Bayes' theorem applied to patient judgments, to a combination of patient judgments and objective data, and to objective data.

Disease	Test	Mean judged probability of disease after positive test No. (SD)	Mean calculated P(D/T+) using patient's pretest probability, sensitivity, and specificity No. (SD)	Mean calculated P(D/T+) using patient's pretest probability, true sensitivity, and true specificity No. (SD)	P(Disease/ Positive Test) using physicians' prior judgment, true sensitivity, and true specificity
Small bowel obstruction	Abdominal x-ray film	.80 47 (.30)	.74 47 (.34)	.81 47 (.23)	.45
Pulmonary embolus	Arterial P_{O_2}	.78 51 (.26)	.58 51 (.37)	.52 52 (.29)	.21
Streptococcal infection	Throat culture	.79 49 (.30)	.64 48 (.35)	.94 49 (.09)	.92
Human immunodeficiency virus	ELISA blood test	.73 53 (.32)	.58 52 (.37)	.93 53 (.11)	.90
Herniated lumbar disk	CT scan	.80 50 (.27)	.71 50 (.35)	.59 50 (.27)	.12
Acute myocardial infarction	ECG	.79 54 (.31)	.68 54 (.36)	.90 55 (.13)	.88

P(D/T+) denotes the probability of disease, following a positive test; No. denotes the number of people the average is based on; SD denotes standard deviation.

and the test sensitivity and specificity could deduce the probability of disease after a positive test result, once he or she has estimated the first three, if the patient knew how to apply the Bayesian calculation. Each patient's judgment can be evaluated in terms of consistency with his or her earlier judgments. To seek the source of error in the patients' judgments of posttest disease probabilities, we have applied Bayes' theorem to the pretest disease probability, sensitivity, and specificity in three ways (Table 2).[19]

In each of the six vignettes the patient judged the posttest probability to be higher than the probability calculated by applying Bayes' theorem to the patient's own judgments of pretest probability, sensitivity, and specificity (first and second columns). This judgment was significantly higher (t test, $P < .05$) for all but the small bowel obstruction vignette ($t = 1.8$, $df = 46$, $P = .08$). There are 30 additional paired comparisons (5 more between-column comparisons for each of the six vignettes). Twenty-five of them are significant at $P = .05$ or less, and two more have P between .05 and .10 (data available on request). This suggests that no one element of the patients' judgment is primarily responsible for the inaccurate posttest probability estimates. Rather, the inaccuracy of the patients' posttest probability judgments is produced jointly by errors in the patients' judgments of sensitivity, specificity, and the pretest probability, as well as by the way the patient combines those judgments.

DISCUSSION

Patient Accuracy

This study showed that patients have very inaccurate knowledge about the pretest and posttest probabilities of six common diseases, and about the characteristics of typical tests used to diagnose those diseases. A recent assessment of patients' understanding of the effects of an intervention (breast cancer screening) reported a similar finding.[20] This inaccuracy is not surprising, and may be completely appropriate; it is the physician's job, not the patient's, to appreciate disease differences in diagnostic uncertainty.

Patients do have reasonable generic expectations about disease probability and test accuracy. Their pretest probability for any suspected disease is less than half (mean 41.3%, median 35.0%) and after a positive test result they think the probability is much higher (mean 78.2%, median 95.0%). Thus, they recognize that when a disease is suspected this does not mean one has it, and they think that after a positive test result the probability increases greatly. They acknowledge the possibility that a diagnostic error might occur (sensitivity: mean 73.1%, median 90.0%; specificity: mean 72.6%, median 90.0%), but they do not know which diseases have accurate tests, and they think a false-negative result is as likely as a false-positive.

Experience

Among the participants in the study were patients who had had experience with each of the diseases. At only one of the two clinics, subjects with disease experience had significantly more accurate knowledge about test specificity and about disease probability after a positive test result. However, this effect is very small, and patients with disease experience still made very inaccurate judgments. This implies either that their physicians had not explained the diagnostic uncertainty, that the patients had not understood the explanation, or that the patients had forgotten it.

Probabilistic Inference

The patients' intuitive judgment of the probability of the disease following a positive test result was larger than the posttest probability calculated by Bayes' theorem, using the patient's own estimates of prior disease probability, sensitivity, and specificity. This result was statistically significant for five of the six disease vignettes, and nearly significant ($P < .10$) for the sixth vignette. This means that the average patient overadjusts to the evidence, compared with the adjustment prescribed by Bayes' theorem. This is consistent with some[21-24] but not all[25] observations of untrained subjects. However, physicians may have a better sense of the impact of test results. In a recent study, physicians' average estimate of the posttest disease probability was only slightly lower than the Bayesian extrapolation from their own pretest probabilities and their own estimates of the test characteristics.[19,26]

Limitations of the Study

Study weaknesses may limit the generalizability of the finding that patients have inaccurate knowledge of disease probabilities and test characteristics. We do not know the response rate or the demographic characteristics of the respondents in comparison with the typical patient at each clinic. If only those patients who understood the questions completed the questionnaire, then the average patient may have even less knowledge of diagnostic probabilities than is shown in the results.

Is it possible that patients know disease probabilities and test characteristics accurately but were confused by the response scale? This is unlikely because the average answers are consistent with a belief that a positive test increases disease probability. This suggests that patients could use the response scale.

The mean of three clinicians' judgments was the standard for evaluating patients' judgments of pretest disease probability. The accuracy of this standard is not known. However, the patients on average judged all six diseases to have about the same pretest probability, so patient judgment would be inaccurate unless the true pretest probability for all six diseases was truly 38% to 50%, which is not likely.

Patients were asked their experience with the disease but not with the particular test. Further, the patient may have confused the named test (eg, throat culture for streptococcal infections) with another test for the same disease (eg, rapid strep test), which might have test characteristics closer to the patient's answer. Since the patient judgments for both sensitivity and specificity for all six diseases were approximately the same, their inaccuracy is evidently not due to a misleading questionnaire.

Implications for Physicians

That patients possess inaccurate knowledge of probabilities and test characteristics for diseases they do not have is, in itself, no more important than citizen ignorance of engineering or geography facts. That patients who have experience with the disease still know little about these disease probabilities and test characteristics is more troubling. It suggests physician failure to conform to the legal and ethical requirements that patients should be informed about their diagnosis and treatment,[27,28] including any inherent risks and uncertainties.[1] It is also inconsistent with a view of the doctor-patient relationship, popular with approximately half of patients,[2, 29-35] that calls for full patient participation in decisions about their health.

We suspect that patients who had experienced a disease judged its probabilities inaccurately not only because of their "innumeracy"[20] but also because during that earlier episode their physician had not used probabilities to explain the disease.[36] In a workshop at a recent meeting of the Society of Teachers of Family Medicine,[37] participants role-played conversations between doctor and patient concerning screening for diseases such as breast cancer and prostate cancer. The participants were amused to discover, as they discussed the role-playing exercises, that those playing the doctor role would often express variations in the degree of certainty conveyed by screening test results by using the same words, varying only the tone of voice. Thus, for a positive result with high accuracy, they might say "It is not certain" with a more ominous tone than for a positive result with low accuracy. During discussion, the physicians explained that they do not know the actual probabilities and they are not confident that patients can understand data presented as probabilities. The challenge presented to participants by the workshop faculty, and more generally by those advocating that all aspects of medicine be evidence-based, is to communicate this evidence in the best available terms. Surely it is appropriate to discuss uncertainties using summaries of expectations based on actual data, whether they be presented in relative frequencies (probabilities) or absolute frequencies. A statement that "1 out of 10 people like you with a positive screening result would actually have cancer" is more informative than "It is not certain that a positive result would mean you have cancer," even if the latter statement is delivered with a mildly ominous tone.

A recent study observing patient-physician interaction concluded that physicians discuss with patients only a fraction of the ideas necessary for a full understanding of a decision.[36] We believe that if doctors would explain uncertainties, using explicit probabilities, patients would have a more realistic appreciation of their situations and their options.[1,38] The benefits of an explicit probabilistic explanation of diagnostic uncertainties are analogous to the benefits of explicit probabilities in weather reports: The patients can use the information to assess their situation and make decisions about it. Patients without this understanding may make mistakes, such as worrying excessively about a very low probability of disease or assuming they are free of a disease that has not yet been ruled out.

Physicians, too, may benefit from explicit probabilities. For example, their estimates of mammography sensitivity and specificity were recently shown to be no more accurate than patient estimates.[39]

How Should Doctors Communicate with Patients About Diagnostic Uncertainty?

Our study shows that patients lack both the facts about the uncertainty of particular diseases (pretest disease probability, and test sensitivity and specificity) and also the skill of revising their own estimates of those facts to produce an updated estimate of disease probability. In cases where it matters, the physician could provide the facts and help the patient interpret those facts. To convey the rates or probabilities, and to help the patients understand what the probabilities are based on, a physician should speak in terms that patients can easily understand. For example, it has been argued that people understand the basis for posttest probabilities better if expressed in terms of absolute counts rather than conditional probabilities.[17,40] The paragraph below illustrates a conversation with a woman in her 40s about breast cancer screening, where the pertinent probabilities are that approximately .0004 of women in this age group have an undetected cancer at any given time, that the sensitivity of mammography (probability that any abnormality will be detected if the woman has a cancer) is approximately .90, and the specificity is approximately .94.[41] The conversation uses absolute frequencies.

> Imagine 100,000 women your age being tested for breast cancer. Of them, 40 have breast cancer and 36 of the 40 have an abnormal mammogram. Of the remaining 99,960 women who do not have breast cancer, 5998 will also have an abnormal mammogram and 93,962 will not. Thus, 36 of the 6034 women who have an abnormal mammogram will actually have breast cancer.

Most people find this approach easier to understand than explanations in terms of probabilities, and so this form has been recommended as a way to communicate with patients about uncertainty.[40] In addition to adopting a vocabulary that makes the probabilities understandable, using visual aids, such as 2 x 2 tables relating diseases to tests[42] and tree representations of the same concept,[39,43] may help patients grasp the logic of diagnosis in the face of uncertainty.

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