# Risk Communication in Clinical Practice: Putting Cancer in Context

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***Context:*** **Clinicians are increasingly urged—even mandated—to help patients make informed medical decisions by paying more attention to risk counseling. For many, the role of risk counseling is new and unfamiliar. This effort is made more difficult given the practical constraints created by 15-minute visits and competing demands (e.g., patient's chief complaint and institutional needs).** ***Objective:*** **We detail a three-part approach for improving risk communication, acknowledging the role of clinicians, patients, and other communicators (i.e., media or public health agencies).** ***Proposed Approach: Office-based tools to help clinicians do more.*** **We suggest two ways to help make up-to-date estimates of disease risk and treatment benefit easily available during office visits. We propose the development of a comprehensive population database about disease risk and treatment benefit to be created and maintained by the federal government.** ***Educating patients.*** **We propose "Understanding Numbers in Health" a tutorial that reviews basic concepts of probability and their application to medical studies to help people become better critical readers of health information.** ***Guidance for communicators.*** **Finally, we propose a writer's guide to risk communication: a set of principles to help health communicators present data to the public clearly and objectively.** ***Conclusion:*** **In addition to tools to help clinicians better communicate risk information, serious efforts to improve risk communication must go beyond the clinic. Efforts that help the public to better interpret health risk information and guide communicators to better present such information are a place to start. [Monogr Natl Cancer Inst 1999; 25:124–33]**

## INTRODUCTION

Clinicians are increasingly urged [even mandated *(1)*] to do better risk counseling to help patients make informed medical decisions. The central counseling role that clinicians are expected to play is typified by the recent National Institutes of Health (NIH) Consensus Panel on breast cancer screening for women ages 40–49 that stated that ". . . a woman should have access to the best possible information in an understandable and usable form. Her health care provider must be equipped with sufficient information to facilitate her decision-making process" *(2)*. Unfortunately, the high expectations articulated in this and similar recommendations rarely are accompanied by practical advice.

There are several reasons why efforts focused on the clinician may have limited effect in improving risk communication. First, for many clinicians, risk communication is an unfamiliar discipline. The emphasis on the patient's role in medical decisions is a relatively recent phenomenon (i.e., shared decision making) *(3)*. Few clinicians receive training in methods to promote effective communication with patients (about risk or any subject), and, in fact, little is known about the best ways to communicate such information. Moreover, the relevant data to be communicated have only recently become available and are not easily accessible at the time of office visits.

Second, the competing demands of clinical practice limit what clinicians can be expected to do within the real-world constraint of the standard 15-minute visit *(4)*. The clinician first must address the patient's chief complaint, the concerns and symptoms that brought the patient to the office (which is usually not "I need help to make sense of the health risks I face"). In addition, the growing institutional demands aimed at measuring and at improving the quality of health care have already left many clinicians feeling burdened. These demands invariably result in increased paperwork for data collection and for monitoring adherence to practice guidelines. Given the foregoing, it is not surprising that the limited data available suggest risk is rarely discussed in typical clinical encounters *(5)*.

Risk communication is particularly important in discussions about cancer. Because cancer is an especially dreaded diagnosis, information about the chance of developing cancer or the effect of various preventive strategies in reducing cancer risk or the chances of dying of cancer may be extremely welcome. However, information about cancer alone (or a particular cancer) may overemphasize the risk compared with other health issues. In this paper, we focus on ways to improve the presentation and

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*See* "Notes" following "References."

interpretation of quantitative data about risk in general (Table 1). First, we make suggestions for simple office-based tools to help clinicians communicate about prevention. Next, we discuss a strategy for educating patients to be better consumers of data. We conclude with guidance for communicators to improve the quality of data disseminated to the public by news media and public health agencies.

## Office-Based Tools: Helping Clinicians Communicate the Value of Prevention

### Rationale

A fundamental goal of health risk communication is to help people better understand the important health risks they face. This goal, a basic concept of contemporary medical ethics *(3)*, also has practical implications. Patients who received more information from their physician were more satisfied and had higher compliance with medical regimens *(6)*. At a minimum, understanding the magnitude of a risk (i.e., how big of a threat is breast cancer to me?) entails having some idea of what the risk is (what does it mean to have breast cancer?) and the chances of developing or dying of the condition. Although it is often assumed that physicians spend much time communicating with their patients about risk, remarkably little is known about if and how such communication actually occurs. In the one study *(5)* documenting doctor–patient risk communication (defined as discussion about behavior change, compliance with screening tests, or preventive treatments), risk was discussed in only 26% of primary care visits and was described numerically in only 3%. One reason why physicians may not engage in risk communication with patients is that they lack easy access to the relevant data. Simple office-based tools may help overcome this barrier.

Office-based tools may be of value in stimulating and in facilitating discussions about disease risks. Patients may want to know the answer to questions such as, what is the chance that a person my age will die of heart disease or breast cancer in the next 10 years? Similarly, patients may also find information about the benefit of various risk-reducing strategies valuable: for example, how does my chance of dying of breast cancer change if I have annual mammograms? To be useful, such office-based tools need to be up to date, immediately available, and easy for both clinicians and patients to use and to understand.

### Disease-Specific Tools

A number of tools that generate disease-specific risk estimates for an individual patient are now available. For example, the American Heart Association *(7)* has a web site where an individual's risk of myocardial infarction can be calculated with the use of a model generated from the Framingham data. The Northern New England Cardiovascular Group *(8)* uses a preprogrammed hand-held computer to provide patients considering coronary artery bypass graft surgery with an estimate of the mortality risk they face from surgery. Recently, the National Cancer Institute (NCI) *(9)* issued the Breast Cancer Risk Assessment Tool that provides women with their risk of developing breast cancer to help women contemplating tamoxifen for the primary prevention of breast cancer.

Implementing these tools in clinical practice entails collecting the necessary risk factor information from patients [e.g., the breast cancer risk factors required for Gail model *(10)* could be collected before a clinic visit] and generating a risk report. Such risk reports could then be attached to each patient's chart at the time of a scheduled clinic appointment with their clinician to maximize the chance of discussion. Some evidence *(11–13)* suggests that such personalized messages may be more effective than generic messages. Whether the extra time, cost, and technical difficulty of these personalized reports outweigh this potential advantage is unknown.

Although such tools are appealing because the disease-specific estimate is personalized, the inherent focus on a single disease taken out of context may overweigh its importance. When making a decision, a patient may find it helpful to understand where this particular disease fits into the important health threats he or she faces. Patients may find it particularly helpful to know: How does my chance of dying of this particular disease compare with other diseases? What is my overall chance of dying? How does the overall mortality benefit of one intervention (e.g., mammography) compare with the benefit of another (e.g., giving up cigarettes)?

**Table 1.** Proposed three-part approach to improve health risk communication*

| Component | Problem | Proposed approach |
|---|---|---|
| Clinical encounter | Physicians infrequently discuss risk with patients and rarely use quantitative terms in such discussions | **Office-based tools**<br>Help clinicians to do more<br>• Disease-specific tools<br>Collection of risk factor data to generate personalized disease risk estimates for clinic visit (e.g., NCI Breast Cancer Risk Assessment Tool)<br>• Comprehensive tools<br>Wall charts with age- and sex-specific population data about disease risk and benefit of interventions (Tables 2–3) |
| Patient comprehension | Low levels of numeracy and susceptibility to framing are important barriers to patient comprehension | **Patient education**<br>Teach patients to be better consumers of data<br>• General education<br>Primer to teach patients about numbers in health and how to rate the quality of scientific evidence |
| Media messages | Misleading messages contribute to unrealistic beliefs about treatment benefit | **Guidance for communicators**<br>Improve quality of data patients see<br>• Set of guiding principles (Table 4) |

*Each approach will require evaluation for feasibility and effectiveness. NCI = National Cancer Institute.

## Comprehensive Tools: Disease Risk and Benefit Wall Charts

To provide this context, we propose the creation of charts with age- and sex-specific data about disease risks and treatment benefits. Tables 2 and 3 present examples of such simple office tools. Such low-tech tools, although lacking the glamour of interactive computer applications, have several distinct advantages. Simple tools are inexpensive and could be used anywhere (e.g., posted in any clinic office). Furthermore, simple tools require no special hardware and no additional personnel or maintenance.

### *Disease Risk Chart*

The disease risk chart shown in Table 2 displays 10-year disease-specific mortality data for five major diseases—in this case, coronary artery disease, breast cancer, lung cancer, colorectal cancer, and ovarian cancer—for women within 5-year age categories *(14,15).* Moving across the table allows the user to compare the magnitude of each disease risk. Because many people may be even more concerned about their overall chance of dying, the final column displays all-cause mortality to provide context about how much each disease contributes to the overall chance of dying. Whereas mortality data can be represented as counts, proportions, or rates, we use counts with a stable denominator (e.g., 100 000 women) in our example, because there is some evidence *(16,17)* suggesting that people find counts easiest to understand.

### *Benefit Chart*

Table 3 presents an example of a benefit chart. The goal of this chart is to help patients compare the relative effect of a change in behavior or specific intervention on all-cause mortality. Our example displays age- and sex-specific 10-year all-cause mortality with or without a given intervention. The numbers shown in the chart are crude estimates that are accurate in terms of order of magnitude. The first scenario in the chart considers 100 000 smokers and displays their chance of dying in the next 10 years if they all continue to smoke or if they all quit smoking and the net effect—about 6500 deaths prevented among 55–59 year-old smokers. Another scenario considers 100 000 women who do not have an annual screening mammography and those who do and shows the net effect of 200 deaths prevented for 55–59 year-old women. These examples show that, for a 55-year-old female smoker, giving up cigarettes has a substantially greater effect on all-cause mortality than annual mammography.

Ideally, we would create a benefit chart for an intervention only if the efficacy of screening or behavioral changes has been demonstrated in randomized trials (e.g., mammography for women in their 50s) or when observational analytic studies have convincingly demonstrated benefit and the interventions are routinely recommended (e.g., Pap screening for cervical cancer, smoking cessation). Because age and comorbidity (i.e., competing risks of disability or death that patients face in addition to the risk under consideration) will importantly influence the benefit of any intervention (behavioral changes or screening tests), the benefit charts may encourage explicit discussion between the patient and clinician about these issues. Because interventions can also have harms, an important challenge remains in how to convey data about side effects, bad outcomes, and so forth. Studies comparing the effectiveness of our proposed comprehensive tools, disease-specific tools, and usual care are needed to learn which better helps patients make important medical decisions.

## Data Source for Charts

The data required to construct such charts are currently available from a variety of sources [e.g., statistical abstracts, the

**Table 2.** Disease risk chart for women*: estimated 10-year disease-specific and all-cause mortality

| | Imagine 100 000 women your age. Over the next 10 years, how many will die of | | | | | |
|---|---|---|---|---|---|---|
| | Coronary disease† | Lung cancer | Breast cancer | Colorectal cancer | Ovarian cancer | All causes |
| For women age (y) | | | | | | |
| 20–24 | 8 | 1 | 6 | 2 | 2 | 600 |
| 25–29 | 30 | 5 | 30 | 6 | 5 | 700 |
| 30–34 | 70 | 20 | 70 | 10 | 10 | 1000 |
| 35–39 | 140 | 50 | 150 | 30 | 20 | 1500 |
| 40–44 | 300 | 130 | 270 | 50 | 50 | 2100 |
| 45–49 | 630 | 310 | 420 | 100 | 90 | 3300 |
| 50–54 | 1200 | 600 | 550 | 180 | 150 | 5100 |
| 55–59 | 2200 | 1000 | 680 | 300 | 210 | 8100 |
| 60–64 | 3900 | 1500 | 830 | 440 | 280 | 12 000 |
| 65–69 | 6500 | 1800 | 970 | 640 | 350 | 18 000 |
| 70–74 | 11 000 | 2000 | 1100 | 880 | 400 | 27 000 |
| 75–79 | 18 000 | 1900 | 1200 | 1200 | 440 | 41 000 |
| 80–84 | 34 000 | 1500 | 1200 | 1500 | 400 | 67 000 |
| 85+ | 42 000 | 940 | 1100 | 1500 | 300 | 79 000 |

*We obtained 1996 mortality rates for 5-year age groups from Surveillance, Epidemiology, and End Results Program (cancer rates) and National Center for Health Statistics (coronary disease, all-cause mortality). We converted these annual rates into 10-year probabilities by applying the age-specific, disease-specific, and all-cause mortality rate for adjacent 5-year intervals. Numbers have been rounded to facilitate interpretation and represent rough estimates that should be accurate in terms of order of magnitude.

For example, about 8 of 100 000 women age 20–24 will die from coronary artery disease in the next 10 years compared with 3900 out of 100 000 women age 60–64.

†Coronary artery disease includes deaths attributed to acute myocardial infarction, old myocardial infarction, angina, ischemic heart disease, and subacute/acute forms of ischemic heart disease.

**Table 3.** Prototype benefit chart for women: 10-year all-cause mortality with and without intervention and deaths prevented (95% confidence interval)

| Imagine 100 000 women your age. Over the next 10 years, how many will die if they | | | | | | | | | |
|---|---|---|---|---|---|---|---|---|---|
| | Quit smoking | | | Start annual screening with mammography | | | Start annual screening for colon cancer* | | |
| Age (y) | No | Yes | Deaths prevented | No | Yes | Deaths prevented* | No | Yes | Deaths prevented* |
| 55–59 | 13 000 | 6500 | 6500 (5000–8000) | 8100 | 7900 | 200 (100–300) | 8100 | 8000 | 100 (90–110) |

*These numbers assume that the reduction in disease-specific mortality observed in trials is extended to all-cause mortality. Reductions in all-cause mortality have not been consistently observed in these screening trials. These estimates, therefore, represent best-case scenarios.

National Center for Health Statistics, and the Surveillance, Epidemiology, and End Results (SEER) Program[1]] but would be difficult to consolidate and update. A health risk database could be developed, maintained, and made publicly available by the federal government. Such a central repository of risk information would serve the public good in much the same way as Statistical Abstracts of the U.S. or other federally maintained databases. A distinct advantage of a federal agency taking on this responsibility would be to minimize the incentives to advocate for a specific disease. The National Center for Health Statistics already collects disease data and would be an ideal candidate for the disease risk chart. Because benefit data would require more critical interpretation of the literature, the Agency for Health Care Policy and Research, with its interest and expertise in evidence-based medicine, would be a natural choice for this responsibility.

## Patient Education: Teaching Patients to Be Better Consumers of Data

### Rationale

Efforts to promote informed patient decision making have become increasingly common. In general, these efforts have focused on providing disease-specific facts. The rationale underlying this approach is straightforward: to make informed decisions requires information. If people lack key facts, their decisions cannot be informed. The solution, then, is to provide the facts.

Unfortunately, there are reasons to question the likely effect of this commonsense approach to patient education. First, patients may not be ready for the data. That is, problems with numeracy (i.e., low quantitative literacy) are common. For example, in the National Adult Literacy Survey *(18),* 47% of adult Americans could not calculate the difference between regular and a sale price from an advertisement. Low levels of numeracy strongly relate to difficulty in making use of quantitative data about the risk reduction of screening mammography *(19).* Second, patients may not know how to interpret the information they are given. Educators have long understood that presenting facts without first preparing the audience to receive them (i.e., integrate them into some organizing structure) is ineffective and probably counterproductive. In such a case, the members of the audience will absorb little information (which will be quickly forgotten), will not understand how the information fits into their own experience, and may misinterpret what it means. With little experience in using data, for example, patients may be especially susceptible to the framing effects frequently discussed in the cognitive psychology literature (i.e., how simple changes in the format of otherwise identical numerical information can profoundly influence its interpretation) *(20–26).*

To see how well patient educational materials convey quantitative data to patients under the best of circumstances, we performed a structured literature review *(27)* to identify randomized trials of interventions designed to communicate quantitative data about disease risk or treatment benefit. Of 70 trials studying patient education interventions, only four attempted to provide patients with some sort of framework for approaching a medical encounter (although none dealt with the interpretation of quantitative data). The rest presented facts without any interpretative framework. Whereas the majority of these trials sought to convey quantitative data (n = 47 articles), we found only seven randomized trials evaluating patient comprehension of these data *(19,28–33).* The table in the Appendix summarizes the results of five of the seven trials that tested a patient education tool *(28–32).* Although it is difficult to compare across studies because the interventions and metrics of efficacy are quite diverse, the interventions had variable effects and, in general, left substantial room for improvement.

### Tutorial: Understanding Numbers in Health

Rather than relying on clinicians and communicators to interpret information for the public, we propose to develop the public's capacity to be critical consumers of health information—to prepare patients to receive data. Our proposal consists of creating a generic patient's user guide to health information that deals with the following five subjects.

1) *What is risk?* Attempts to discuss medical risk are easily undermined by confusing and imprecise use of language. The tutorial begins by addressing common sources of confusion (multiple meanings of the word "risk"), how to use words (and the limits of words) in describing risk, and ways to quantify risk (probability, percents, proportions, and rates). We will also introduce the reader to a scale that we have developed to facilitate quantification and communication of risk—particularly small risks less than 1% (Fig. 1).

2) *What to look for in a statement about risk.* This section teaches the reader to look for various essential elements in statements about risk. Readers will be sensitized to ask questions, such as: What is the risk under discussion (e.g., is it the risk of being diagnosed or of dying?)? What is the time frame under consideration (e.g., next 5 years or lifetime—and what does "lifetime" mean?)? Who is at risk (i.e., does the

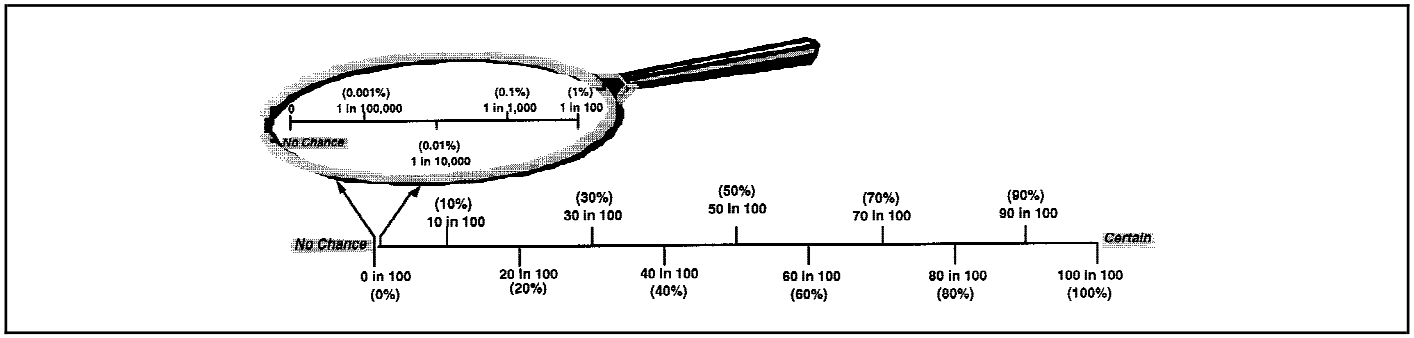


**Fig. 1.** Visual scale for representing event probability.

statement refer to all women? women of a certain age? women with specific characteristics such as a family history of breast cancer?)?

3) *Putting risk in context.* A salient but rare outcome, such as a celebrity dying of a rare cancer, may give undue weight to certain health risks. The tutorial emphasizes the need to put risks into perspective. Readers will be encouraged to ask questions, such as: How does the chance of this disease compare with other diseases or other familiar events? How dangerous is the disease (i.e., appreciating the difference between developing a condition and dying of it)? To illustrate competing risks, we will make use of disease risk charts discussed previously.

4) *Changing risk.* This section focuses on how to interpret statements that measure changes in risk given some exposure or intervention (e.g., relative and absolute risk reduction or number needed to treat) and introduce the concept of framing (e.g., dying versus not dying). Benefit charts could be used to highlight that not all risk factors and interventions are equally important.

5) *Evidence.* The final section points out that there is uncertainty in what we know and introduces the idea of grading evidence by highlighting basic concepts of study design (e.g., observational study versus randomized clinical trial). We encourage readers to have a healthy skepticism and ask themselves, "Can I believe what I am being told? Could it be wrong?"

### Limitations

Our approach has several potential problems that should be acknowledged. First, some patients say they do not want information. Many of these patients would therefore have no interest in our tutorial. It is possible that for some people, however, an expressed lack of interest in information may really mean they are afraid they will not be able to understand what they are told. Our tutorial may make quantitative information accessible to people who might otherwise have given up. Next, patients' interest in the tutorial may change substantially under different circumstances. For example, it is possible that patients facing new and serious decisions (e.g., at the time of learning a new cancer diagnosis) may feel too emotionally overwhelmed to make use of the materials, whereas patients making decisions under less intense circumstances (e.g., an older man considering prostate-specific antigen screening) may find the materials especially useful. Finally, understanding whether the tutorial succeeds in teaching (i.e., what do patients learn?) and whether the materials help people make decisions will require careful study and will be the subject of future research.

### Application

Assuming that we are able to demonstrate that the tutorial is usable, acceptable, and effective in a randomized trial, we could envision the tutorial being used in a variety of settings. The tutorial could be available for use in school curricula (i.e., modeled on "Chance," an Internet-based, quantitative literacy course that is based on current chance events in the news and is available at: http://www.dartmouth.edu/%7Echance/Chance.html). In clinical settings, the tutorial could be distributed as part of general patient orientation to a practice or could be distributed at the time that important decisions are being made (e.g., men newly diagnosed with prostate cancer or women newly diagnosed with breast cancer deciding on a treatment course) and interpretation of data becomes critical.

## Guidance for Communicators: Improving the Quality of Data That Patients See

### Rationale

Communicators face the difficult task of translating—often under short deadlines—complex, probabilistic information into a format accessible to a general public with limited grounding in science and with limited ability to make use of probabilistic information *(18,19).* Communicators themselves may have only superficial training in the critical evaluation of medical literature. They may be unprepared to recognize potential biases, methodologic weaknesses, or questionable statistical manipulations that ought to raise caution about the validity or generalizability of a study's results. For example, the case for cancer screening is often made with a statement that the 5-year survival of patients diagnosed with early stage cancers is much greater than that of patients diagnosed with later stage cancers. These inherently biased statements do not demonstrate that screening is beneficial. Rather, these statement simply say that patients diagnosed earlier live with a cancer diagnosis longer *(34,35).* It is only from the results of randomized trials that demonstrate that those who are screened have lower cancer death rates than those who were not screened that we can know the true effect of screening.

Evaluation of the accuracy of communications targeting the general public are limited, but frequent problems with news reports have been demonstrated *(36,37),* and a recent review *(38)* of Australian public health brochures about screening mammography documented unbalanced and incomplete presentation of data, suggesting an underlying attempt to persuade rather than inform.

## Guidance for Communicators

Table 4 presents a set of principles that we hope will guide communicators in how to present the data completely, objectively, and understandably. To illustrate some of these principles, we will use examples from the NCI's "Breast Cancer Risk Tool: An Interactive Patient Education Tool" *(9)*.

### *Delineate the Main Message Clearly*

**Breast cancer risk.** Fig. 2 shows the NCI screen that displays the main message about breast cancer risk. A woman's Gail risk factors are entered, and then her calculated breast cancer risk is displayed graphically and described in text as follows:

> "Estimated risk for invasive cancer over the next 5 years is 0.6%"

> "Estimated risk for invasive cancer over her lifetime is 11.1%"

The NCI tool has done well in clearly defining this main message: the outcome under consideration is clearly stated as the 5-year and lifetime (to age 90) risk of a diagnosis of invasive breast cancer.

**Table 4.** Guiding principles for communicators

| |
|---|
| **Delineate the main message clearly** |
| Define the outcome under consideration |
| Diagnosis, specific morbidity, or death from disease |
| Provide the time frame (e.g., in the next 10 years) |
| Present data clearly |
| Some formats are hard to understand and should be avoided |
| e.g., "1 in ____" or expressing small risks with percentages alone (i.e., 0.01%) |
| Better formats use counts and balanced framing |
| e.g., Imagine 1000 people: 100 people will die from cancer, 900 people will not |
| Clearly specify to whom the data apply (e.g., gender, age, risk factors) |
| Present benefit and harm symmetrically |
| When expressing changes in risk, present absolute event rates or absolute changes from baseline risk |
| **Provide context** |
| Present both chance of diagnosis and death to reflect disease lethality |
| Specify important competing risks for death |
| Disease under consideration may be a less important contributor to a person's overall chance of dying than other diseases (e.g., prostate cancer versus heart disease for 75-year-old man) |
| Compare with familiar events |
| Help to calibrate reader to risk magnitudes by providing chance of events generally acknowledged to be common (e.g., catching a cold) or extremely rare (e.g., being hit by lightening) |
| Benchmark factor (risk factor or intervention) under consideration against other known factors to be clear that all factors do not change risk by the same amount |
| **Acknowledge uncertainty** |
| Be explicit about uncertainty by presenting some measure of estimate precision (e.g., 95% confidence interval) |
| Extrapolate cautiously from a single study, intermediate end point (e.g., tumor shrinkage), or across populations; express grater caution about inferences from weaker data (e.g., observational study) |
| In the special case of screening, remember that the benefit can only be shown in randomized trials; improved 5-year survival for cancers detected by screening is not proof of benefit |
| **Remember health** |
| Scary messages do not make people feel healthier and may generate unrealistic expectations about disease risk and treatment benefit |

Risk is expressed as a percentage in text and on a linear percentage scale (i.e., 0%–50%, marked with 5% increments). This dual presentation is a particularly good idea because many people have trouble working percentages alone *(18,19)*, especially percentages less than 1%. For example, only 20% of female veterans—almost all of whom had graduated from high school—were able to correctly convert 0.1% to 1 in 1000 *(19)*. There is surprisingly little guidance available on how best to present such quantitative information. Some prior studies *(16,17)* suggest that counts (e.g., imagine 1000 women, 10 die) may be easier to understand than percentages, and, in a recent study *(39)*, we demonstrated that people have great difficulty with expressions of the form "1 in ____." Unfortunately, the design of the graphic in Fig. 1 is not ideal. It is practically impossible to indicate probabilities below 1% (a relevant range for many likely users). One approach to this problem is to use a scale, like the one shown in Fig. 1, designed to facilitate expression of small probabilities.

**Benefit of tamoxifen.** The NCI tool has a second main message that is to inform women about the benefit of tamoxifen in the primary prevention of breast cancer. This message is less well done.

> "Women [taking tamoxifen] had about 49% fewer diagnoses of invasive breast cancer"

The benefit of tamoxifen is only expressed as a relative risk reduction without an explicit statement about baseline risk. Several studies *(20–23)* have shown that physicians and patients find the benefit of an intervention more compelling when it is expressed as a relative risk reduction rather than the corresponding absolute risk reduction. Whereas most typical risk reduction expressions may be difficult to understand, the relative risk reduction without the baseline risk—the format used in the NCI tool—is particularly difficult *(19)*. In the Breast Cancer Prevention Trial *(40)*, the baseline risk (the chance per year of developing invasive breast cancer for women in the placebo arm) was 68 cases per 10 000 women per year. Applying the 49% relative risk reduction yields a risk of 34 cases per 10 000 women per year in the tamoxifen arm.

Curiously, one of the more salient potential harms of tamoxifen—an increased chance of developing uterine cancer—is presented using absolute event rates for each group:

> ". . . annual rate of uterine cancer in the tamoxifen arm was 30 per 10 000 compared to 8 per 10 000 in the placebo arm"

This asymmetric framing tends to emphasize the benefit of tamoxifen while minimizing the harm (Fig. 3). If the increased uterine cancer was expressed using the relative risk format, the statement would read ". . . 275% more uterine cancer" and would likely elicit a very different feeling. On the basis of this framing phenomenon, we believe it is important to present both the benefits and harms of a treatment using the same frame. To enhance the effectiveness of such messages, we suggest that communicators present changes in risk using absolute event rates *(19)*.

### *Provide Context*

The purpose of the NCI tool is "to measure a woman's risk of invasive breast cancer." The risk provided is the risk of *getting*

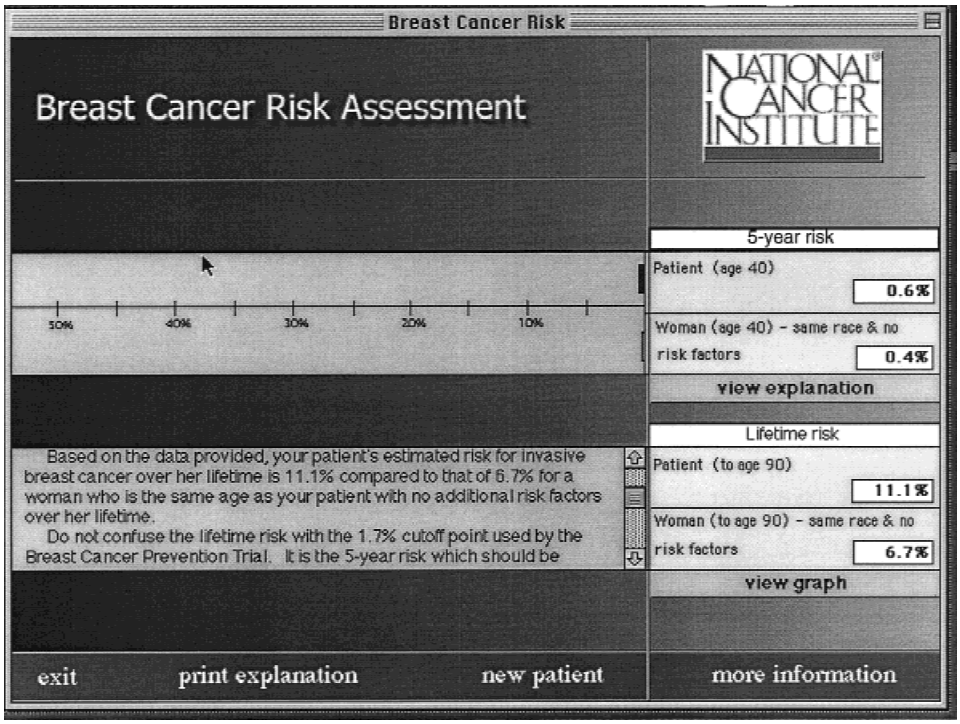


**Fig. 2.** The National Cancer Institute's Breast Cancer Risk Assessment screen displaying a woman's 5-year and lifetime risk of invasive breast cancer.

| | Benefit<br>Breast cancer diagnosis | Harm<br>Uterine cancer diagnosis |
|---|---|---|
| **Actual "frames" used in NCI risk tool** | 49% reduction | Placebo: 8 per 10,000<br>versus<br>Tamoxifen: 30 per 10,000 |
| **Alternate "frames"** | Placebo: 68 per 10,000<br>versus<br>Tamoxifen: 34 per 10,000 | 275% increase |

**Fig. 3.** Asymmetric presentation of benefit and harms of tamoxifen. The actual frames tend to emphasize benefit and minimize harm, whereas the alternate frames have the opposite effect. The numbers shown are the average annual event rates.

breast cancer. For many women, however, the more relevant risk is her chance of *dying* of breast cancer. Presenting incidence data without mortality data fails to provide important context about how often breast cancer results in death. A related issue involves competing risks for death—for example, how a woman's chance of dying of breast cancer compares with her chance of dying of heart disease.

Another important aspect of context relates to calibrating users to the magnitude of the probabilities presented. It has been demonstrated that even experts are often poorly calibrated to the magnitude of various risks *(41)*. Providing comparisons with the chance of familiar events—such as having a minor car accident—may help make the numbers more meaningful. Such comparisons might help users put their breast cancer risk (i.e., numbers like 0.6% given above) into perspective.

In addition, when discussing factors that change risk, it is important to emphasize that all risk factors do not increase risk to the same degree—something that is not done in the tool. For example, a woman may be able to better judge her breast cancer risk by knowing that family history and age raise the chance of breast cancer to a far greater extent that having the onset of menarche at an early age.

### *Acknowledge Uncertainty*

In both the presentation of disease risk and treatment benefit described above, only point estimates (e.g., 49% risk reduction) are provided. These single numbers without 95% confidence intervals imply a false sense of certainty in the expected outcome. This concern is mostly relevant to discussion of treatment benefit rather than disease risk. Whereas the formal statistical definition of 95% confidence intervals may be diffi-

cult to communicate, we suggest a simple statement that uses the lower and upper bound of the confidence interval in the following way:

> "If 1000 woman do not take tamoxifen, six will be diagnosed with invasive breast cancer in the next year. If these 1000 women all take tamoxifen, our best guess is that three of these six women will **not** get breast cancer. It is possible that tamoxifen actually prevents as few as two women or as many as four women from getting breast cancer."

In addition to the uncertainty of statistical estimates, there is uncertainty extrapolating from populations to individuals *(42)*. An approach suggested to convey this kind of uncertainty *(43)* is to use qualifying statements, such as:

> "There is no way of knowing whether you will be one of the women who gets breast cancer. In addition, if you take tamoxifen, there is no way of knowing whether you will be one of the women who benefited from it."

An explicit acknowledgment of uncertainty should also accompany messages based on the results of a single study, intermediate end point, or extrapolations across populations. It is rare that a single study provides a definitive answer about a particular question. Consequently, it is critical to put the results of a single study into the context of similar studies and to grade the quality of the evidence (i.e., give less weight to the results of observational studies or subgroup analyses and more weight to randomized trials). Communicators should be particularly cautious about drawing strong inferences when small differences are reported by studies with weaker designs. Intermediate end points should also raise caution because changes in such end points (e.g., tumor shrinkage) may not translate into clinically important improvements in patient outcomes (e.g., improved length or quality of life). An additional concern is whether the study results are really generalizable to the patients the clinic sees: Would this population have met entry criteria for the trial? Is this disease a relatively minor competing risk for this population?

### *Remember Health*

One of the main objectives of medical care is to improve the health of the population. Recently, health communicators have begun to increasingly focus on increasing individual's awareness of the disease risks they face and in identifying strategies to modify these risks. In many cases, compliance with recommended risk reduction strategies (e.g., screening for colorectal cancer) has been considered suboptimal. To improve compliance, a number of public health campaigns now actively seek to persuade the public to adopt specific preventive strategies. Many campaigns use scare tactics to promote a particular behavior (e.g., "feeling well is sometimes the first sign of colon cancer—get screened today!" or "you can't see it or feel it, but you may have cancer").

Whereas such persuasive tactics may elicit intended behavioral changes, they have other consequences that may paradoxically worsen a population's sense of health *(44–47)*. First, rather than promoting a sense of health, such tactics may simply increase everyone's sense of vulnerability and anxiety about disease. These messages make it clear that no one is really healthy. For example, telling the story of a 30-year-old woman with breast cancer may garner a lot of attention and motivate some older women to undergo screening mammography, but it will probably also frighten many young women who stand to gain little if anything from mammography. Second, these aggressive tactics may convey a false sense of the magnitude and certainty of the benefits of interventions, engendering unrealistic expectations. Finally, the heightened emphasis on taking personal responsibility for reducing one's risk may lead people diagnosed with disease to blame themselves.

Ironically, the increasing prevalence of persuasive messages coincides with a shift in contemporary medical ethics to a shared decision-making model in which the clinician's role is not to persuade patients to adopt a particular behavior (i.e., use any means necessary to get them to eat that fifth daily fruit) but, where possible, to help patients understand the risks and benefits of the options they face so they can make informed choices between them (e.g., "I understand the pros and cons, and I choose to eat this ice cream"). This model places increasing emphasis on the role of patient preferences and values in medical decision making—because physicians and patients may have different interpretations of well-being.

Whether the evidence of benefit for an intervention is questionable or certain, we believe it is important to consider the likely net effect of such tactics on well-being. We argue that the fundamental purpose of risk communication is to provide individuals with the facts they need to make informed decisions. Increasing the public's sense of vulnerability to inspire a healthy behavior undermines well-being and may result in net harm. We encourage communicators to be sensitive about the potential side effects of their messages.

## CONCLUSIONS

Although clinicians clearly need to be part of the solution, competing demands and inadequate training in how to talk to patients about risk limit what clinicians can contribute toward improving the state of medical risk communication. Moreover, use of criteria such as Health Plan Employer Data and Information Set (HEDIS) report cards to measure "the quality of care" by the degree with which practice complies with guidelines rather than on some measure of the quality of decision making creates a perverse incentive to prescribe rather than to discuss treatment options.

By acknowledging the realities of clinical practice, we advocate a three-part plan to improve clinical risk communication.

1) Help clinicians to do more by providing clinicians with simple and efficient office-based tools to generate and display up-to-date risk and benefit estimates

2) Educate patients with a reader's guide for patients to help the public more critically evaluate the ubiquitous health risk data to which they are exposed

3) Disseminate *Guidance for Communicators*, a writer's guide to risk communication to help journalists and public health agencies express risk information in a clear, balanced, and understandable way

Like any intervention, ours will need careful study to evaluate whether it is effective and acceptable to clinicians, communicators, and patients.

**Appendix Table 1.** Summary or prior randomized trials of disease-specific educational interventions that presented quantitative data and tested comprehension

| Health issue (reference No.) | Population | Intervention | Knowledge assessment* | Finding |
|---|---|---|---|---|
| Hormone replacement for postmenopausal women *(28)* | 165 women recruited for trial from health practitioners, clinics, community advertisement | Intervention: Tailored decision aid<br>Control: ACP education pamphlet from the American College of Physicians | *How many women out of ____ will get "disease" in their lifetime*<br>Risk without HRT<br>CHD<br>Hip fracture<br>Breast cancer<br>Risk with HRT<br>CHD<br>Hip fracture<br>Breast cancer | % Women with realistic perceived lifetime risk†<br>Decision Aid / ACP Pamphlet<br><br>57% / 61%<br>81% / 74%<br>71% / 44%<br><br>75% / 23%<br>79% / 33%<br>79% / 51% |
| Breast cancer risk counseling for first-degree relatives of women with breast cancer *(29)* | 200 women identified by relatives under treatment for breast cancer at two major cancer centers | Intervention: 1.5-hour counseling session by trained nurse-educator who told women: "your personal chances of developing breast cancer by age 80 are ___%, or 1 in ___."<br>Control: General health counseling | *Rate your chances of getting breast cancer during your lifetime on a scale from 0 (definitely will not get it) to 100 (definitely will get it)*<br>Before<br>After | % Women extremely overestimating their breast cancer risk‡<br>Intervention / Control<br>64% / 67%<br>63% / 64% |
| Prostate cancer screening *(30)* | 196 men scheduled for general medical clinic in academic center | Intervention: Shared decision-making video<br>Control: No video | *How many untreated men with early stage prostate cancer would die of this disease?*<br>Most or all will<br>About half will<br>Most will not<br>*Does active treatment extend life*<br>Very or pretty sure it can<br>Not sure<br>Very or pretty sure it cannot<br>*How man men with elevated PSA have prostate cancer?*<br>Most or all do<br>About half do<br>Most do not | % Correct answer<br>Intervention / Control<br><br>93% / 41%<br><br>67% / 24%<br><br>72% / 15% |
| Consent for anesthesia *(31)* | 40 patients scheduled to undergo surgery requiring general anesthesia | Intervention: Explicit discussion numerical data<br>Control: Routine care | *Perceived risk elicited with visual analog scale*<br>Nausea<br>Sore throat<br>Death<br>Brain damage<br>Tooth damage<br>Inadequate sedation | % Correct answer<br>Intervention / Control<br>40% / 35%<br>75% / 75%<br>55% / 15%<br>80% / 65%<br>70% / 30%<br>40% / 50% |
| Correct inaccurate perceptions of the chance of four different health risks: heart attack, stroke, cancer, and motor vehicle accident *(32)* | 1317 adult patients recruited from the waiting room of eight family practices | Intervention: Patient estimates perceived risks and is then given computer-generated, individualized feedback derived from population statistics<br>Control: No feedback | *Compared with others your same age and sex, how would you rate your risk of [event] in the next 10 years?*<br>*Using a 5-point scale ranging from "much lower" to "much higher than average"* | Increasing perceived stroke risk among patients who had underestimated<br>Reducing perceived risk of cancer among those who had overestimated<br>No change in perceived heart attack or motor vehicle accident risk |

*CHD = coronary heart disease; HRT = hormone replacement therapy; PSA = prostate-specific antigen.

†"Realistic" means a woman's perceived risk estimate fell in the same quartile as her predicted risk calculated for women with a similar characteristics.

‡Accuracy of risk estimation was calculated as the difference between an individual's subjective estimate and an objective estimate based on the Gail algorithm. "Extreme overestimation" means the subject's estimate exceeded the highest possible lifetime Gail score for a woman of the same age. At follow-up, 89% of control subjects and 82% of intervention patients overestimated their personal risk by at least 10%. Reprinted with permission from Effective Clinical Practice.

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## NOTES

[1]SEER is a set of geographically defined, population-based, central cancer registries in the United States, operated by local nonprofit organizations under contract to the National Cancer Institute (NCI). Registry data are submitted electronically without personal identifiers to the NCI on a biannual basis, and the NCI makes the data available to the public for scientific research.


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