Disclosure and rationality: Comparative risk information and decision-making about prevention

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Abstract With the growing focus on prevention in medicine, studies of how to describe risk have become increasingly important. Recently, some researchers have argued against giving patients “comparative risk information,” such as data about whether their baseline risk of developing a particular disease is above or below average. The concern is that giving patients this information will interfere with their consideration of more relevant data, such as the specific chance of getting the disease (the “personal risk”), the risk reduction the treatment provides, and any possible side effects. I explore this view and the theories of rationality that ground it, and I argue instead that comparative risk information can play a positive role in decision-making. The criticism of disclosing this sort of information to patients, I conclude, rests on a mistakenly narrow account of the goals of prevention and the nature of rational choice in medicine.

Keywords Decision making • Comparative risk • Prevention • Rationality • Expected utility theory • Biomedical ethics

Introduction

As medicine increasingly emphasizes prevention, aiming to do a better job of identifying and reducing patients’ risk of disease, important questions arise about...
how best to describe risk. Psychology distinguishes between two types of risk information. On the one hand is “personal risk,” such as an individual’s chance of developing a specific disease, expressed as a frequency or a probability. On the other hand is “comparative risk,” such as whether an individual’s risk is average, above average, or below average compared to people of the same age and gender. Recent studies show that telling someone that his risk is above or below average has a large impact on his perception of that risk and response to it [1–5].

Some researchers have pointed out that this influence appears to violate the precepts of rational decision-making [5]. For example, when a woman is considering a preventive treatment for breast cancer, it is reasonable to think that she should accept it if the benefits outweigh the risks and other burdens, and reject it if they don’t [5]. In this case, the relevant benefit is the reduction in the chance of morbidity or mortality that the treatment can provide. The risks or burdens include the price of the medication, the need for follow-up testing and doctor visits, and any possible side effects. But all these factors can be assessed without considering whether the individual’s baseline risk is average or above or below average. Therefore, some researchers have argued that the impact of comparative risk information on decision-making represents an irrational bias and conclude that this data should not be provided to patients [5].

In this paper, I examine the argument against comparative risk information, as I will call it, and attempt to show that it is not convincing. The paper will progress as follows. In the next section, I review psychological research into the effect of comparative risk information compared to other methods of framing. Following this, I analyze the argument against disclosing this information to patients and interpret it as resting on a widely accepted account of rational decision-making called “expected utility theory.” I then critique the attack on comparative risk information, first, by pointing out ways that this data can be relevant to rational decisions by patients with certain priorities, and, second, by raising questions about some initially plausible assumptions concerning how to apply expected utility theory to such cases. Finally, I consider wider implications for evaluating medical decision-making, especially in the case of preventive services. The resulting questions and challenges must be addressed in any attempt to improve the provision of preventive services in the future.

**Psychological research into comparative risk information**

**Empirical studies**

Psychological research has shown that comparative risk information has a significant impact on people’s attitudes and actions in many settings, even when

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such responses appear to be irrational [1–5]. For example, subjects who are told they have a personal risk of 60% of causing a motor vehicle accident in their lifetime, but are assured that this is below the average of 80%, judge themselves to be safer drivers and have less interest in driving with care than do those who are told that their personal risk is 30% but that this is above an average of 10% [1].

Similar results have been shown in experiments related to risk of disease. Even when people are given specific information about the risk they have of developing a certain disease, telling them that this risk is above or below that of other people significantly affects their feelings about their own vulnerability and their decisions concerning how to respond [2–4]. Interestingly, this effect is significant whether the comparative group is made up of people of the same age and gender who have average risk [1] or have the lowest possible risk [2], or is made up of people of the opposite gender [3].

Fagerlin et al. [5] studied the impact of comparative risk data on women’s willingness to accept a hypothetical preventive treatment. The researchers gave 254 women a scenario where they were asked to imagine that they have a 6% chance of developing breast cancer in the next 5 years. Half were told in addition that this risk is higher than average (with average set at 3%), while the other half were told that their risk is below average (with average set at 12%). As part of the scenario, the women were told that there is a pill available that cuts the risk of breast cancer in half (e.g. reducing it from 6% to 3%, or from 12% to 6%). Finally, subjects were given a list of the side effects of the pill, including hot flashes in the majority of women taking it, cataracts in 1–2%, and a stroke or heart attack in under 1% [5].

After reading the scenario, the subjects answered a questionnaire where they rated their willingness to take the pill and their belief that the risk reduction would be “significant.” Women in the first group (who were told their personal risk was above average) reported a higher interest in taking the pill than did those in the second group (who were told that their risk was below average). Women in the first group were also more likely to feel that the pill would provide a significant reduction in their risk of breast cancer. Finally, all subjects were asked to rate the helpfulness of the comparative data, and most rated it as extremely or somewhat helpful [5]. In summary, even though all women were assigned the same personal risk of 6%, being told that this was above or below average had a statistically significant effect on their views concerning a possible preventive measure. This fits with earlier research on the impact of comparative risk data [1–4].

The study can be criticized in a number of ways. Perhaps most importantly, since it involves subjects responding to a hypothetical scenario, there is the possibility that actual patients would respond differently, as the authors acknowledge [5, p. 143]. In addition, although the impact was statistically significant, one might question whether it is clinically significant, that is, whether it would make a difference in the decisions of many patients.

There are also a number of questions that the experiment was not designed to answer. For example, the data do not indicate whether the subjects’ interest in the treatment and their view of its significance was increased in patients with above average risk, decreased in patients with below average risk, or both. Research in other settings has suggested that although telling individuals that their risk is below
average has a significant effect, telling them that their risk is above average has a smaller effect, perhaps due to psychological “defense” mechanisms [1, 4].

Psychological theories

There are many possible theories for why people respond to comparative risk data as they do. Perhaps the most widely accepted theory depicts the mind as utilizing a “dual representation” of risk, where one system registers the numerical description of risk while another forms “more intuitive perceptions about whether an event will occur” [3, p. 742]. Thus, personal risk data enters the first track, while comparative risk data influences the second. Fagerlin and colleagues point to such factors when they write,

People’s perceptions of risk are not merely cognitive appraisals of numeric risk (e.g., 6% vs. 7%). They include intuitive and emotional reactions that translate being “high” or “low” into “something to worry about” or “something to be relieved about” [5, p. 143].

Some have labeled this the “gist” impression of risk and have offered various accounts for the role of this factor in people’s response to risk [6, 7].

Other approaches are possible. Many researchers in psychology have shown that human decision-making involves irrational “heuristics and biases” [8, 9], and the response to comparative risk data could be seen as one of these. A different approach could be developed based on theories in evolutionary psychology, which postulate mental modules that could have arisen during human evolution [10]. Given the many areas where comparison of “self to others” might have been adaptive—such as in situations where an individual needs to assess his or her strength, attractiveness, intelligence, etc.—a mental module could have been selected that generates strong responses to comparative information. Such a module could continue to operate now in response to risk information, even when there is more reliable and relevant personal risk information available.

The argument against comparative risk information

The rejection of comparative risk information by Fagerlin and colleagues

After describing the results of their study, Fagerlin and colleagues argue that patients should not be given comparative risk information when they are considering preventive treatments. The researchers write:

We contend that the comparative risk information in this study was uninformative and should not have changed risk perceptions. We believe that a person’s decision should not be based on whether they consider themselves at low or high risk but rather on whether they think that the benefits of the treatment outweigh the associated risks…If a prevention
strategy reduces a person’s risk by half, it should not matter whether others receive greater or lesser benefit from the pill [5, p. 142].

Fagerlin et al. go on to write that the comparative risk information can have “unintended results,” such as leading some women to feel less concerned about their risk of getting breast cancer since it is below average [5, p. 142]. They conclude:

When the goal of communication is to prepare patients to make informed decisions, physicians should probably avoid providing patients with average [comparative] risk information; such information will influence patients even when the information is irrelevant to the decision at hand [5, p. 143].

The authors’ conclusions have a direct pragmatic impact, since the research was inspired partly by an attempt to design a decision aid for women considering whether to take the drug tamoxifen to prevent breast cancer. The risks, potential benefits, and side effects of the treatment in the hypothetical scenario, the authors write, were loosely patterned on this case. And the results of their study convinced them that comparative risk data should not be included in the decision aid, even though women generally ask for such information and the subjects in the study reported that they found it useful [5]. Fagerlin et al. write, “Given the potential biasing effects of comparison risk information, we must ask if it is wise to give patients the information they want, since that information may actually harm them (or at least bias their decision making)” [5, p. 143].

Fagerlin et al. do not explain their rejection of comparative risk information further, but their reasoning is relatively clear. An individual woman should make her decision about whether to take the pill based on whether “the benefits of the treatment outweigh the associated risks” [5, p. 142]. Comparative risk information is thus “potentially biasing” since it may have an impact on a woman’s decision even though it does not carry any information about the risks and benefits that she will experience.

It is important to note that this criticism of comparative risk information has far-reaching implications. Current research in genetics and epidemiology aims to develop ways to identify who is at increased risk for various diseases, partly so that these individuals can be encouraged to make behavioral changes or undergo recommended preventive tests or treatments. Since comparative risk information can be more powerful than personal risk information at influencing the behavior of people with increased risk [11], framing risk data comparatively would be preferable in at least some settings. If the argument against comparative risk information were correct, however, this option would not be available.

Comparative risk data and expected utility theory

To flesh out the argument against comparative risk information more fully, it is necessary to review theories of rational decision-making as applied to this case. According to expected utility theory, each possible state of affairs has a value for a given individual, called its “utility,” based at least partly on the individual’s goals,
interests, values, preferences, etc. [12, 13]. For medical interventions, for instance, outcomes can be measured in terms of Quality Adjusted Life Years (QALYs), falling in a range from 0 to 1, with 0 being death and 1 being perfect health. The expected utility of an action is the sum of the utilities of each of the possible outcomes, weighted by their probabilities. The rationally preferable choice, out of a set of possible actions, is the one that maximizes expected utility.

Consider a decision analysis concerning whether to take the pill described in Fagerlin et al. [5]. For a woman who does not to take it, the two possible outcomes can be described as having breast cancer (probability 6%), and not having breast cancer (probability 94%). For a woman who takes the pill, there are more outcomes to consider, involving the possible side effects. If we make the simplifying assumption that the outcomes are mutually exclusive—e.g., that a woman may get breast cancer or a heart attack, but not both—and assign specific probabilities to each, one way of listing the possibilities would be the following:

- Having breast cancer—probability 3%;
- Having a cataract—probability 1.5%;
- Having a heart attack or stroke—probability 0.5%; or
- Being healthy except for hot flashes—probability 95%.

The final ingredient in constructing the decision analysis is to assign a utility to each outcome, and this is a difficult task. Psychologists and health services researchers struggle with the theoretical and pragmatic challenges of calculating utilities or QALYs, and we will not delve into those issues here. One challenge for assigning utilities is that an outcome such as having breast cancer includes a range of possibilities, from having a tumor that is easily removed to having one that has metastasized, and each specific outcome will have its own probability and utility. Calculating the utility of the more general case—having breast cancer—involves calculating a weighted average of the utilities of the more specific possibilities.

Table 1 presents a list of the utilities for the relevant outcomes for two hypothetical women who are considering taking the preventive pill. Note that for woman A, the preferred action is not to take the pill (expected utility 0.988 > 0.944), while for B the preferred action is to take it (expected utility 2 QALYs and utilities may be more easily measured for a group, such as a population, rather than for individuals. But many normative accounts of decision-making assign utilities to outcomes for specific individuals as well [12], as I will do here.

3 Here, I will assume that “maximizing” involves simply choosing the action with the largest expected utility. Assuming a different way of comparing outcomes, such as satisficing, fails to support the argument against comparative risk information, as discussed in Section “Conclusion: The purpose of disclosure.”

4 These possibilities are listed as the outcomes of having the disease or not, rather than the event of getting the disease or not, since utilities are attached to outcomes rather than events.

5 To be precise, the utility of an outcome is also best estimated for a specific time period, but I will ignore this complication in this discussion.

6 I have assigned the utilities to the two women for the purpose of illustration, so these values should not be assumed to be accurate for any actual people.
The difference between the women, in short, is that the utility of having breast cancer is lower for B than for A (0.6 vs. 0.8), and the utility of living with the various side effects is higher (i.e., B is less bothered by these possible outcomes than A). Which of the two choices is right for each woman depends on these specifics about the utility of the various possible outcomes for her.

This analysis shows further why comparative risk information appears irrelevant to Fagerlin et al. [5]: the calculation of expected utility for each woman does not include facts about whether she has above-average, average, or below-average risk. To formalize this, I will define the term “irrelevant” here as follows:

(I) A piece of information is irrelevant to a decision if that information does not convey information about the probability or utility of any of the relevant outcomes.

Using this notion of “irrelevant,” an intuitive principle based on expected utility theory completes the argument:

(P) Irrelevant information (as defined in (I)) cannot improve, and may interfere with, the rationality of an individual’s decision.

According to (P), it appears that a woman who makes her decision based on comparative risk data is losing sight of the key issue, i.e., whether the pill will maximize her expected utility.

### Caring about risk level

In the next three sections, I critique the argument against comparative risk information. In this section, I argue that comparative risk data is not always irrelevant to decisions about prevention, once we recognize a wider range of factors that may affect the utilities of possible outcomes for individuals. In the next section,
I raise questions regarding principle (P), partly based on consideration of theories of rationality. In the concluding section, I consider consequences for the general evaluation of rationality, disclosure, and decisions in medicine.

Although comparative risk data appears irrelevant to the decision analysis depicted in Table 1, an individual can have desires that make comparative risk relevant to determining the utilities of at least some outcomes for her. In these cases, the information is not irrelevant in the sense of (I). For example, consider a woman who wants her risk of breast cancer to be average or below average. She sees her life as going better if her risk falls in this range, independently of whether she ever actually develops the disease. For her, the utilities of the various outcomes listed in Table 1 may be affected by facts about her risk level. Consider a woman whose baseline risk for breast cancer is above average and will be below average if she takes the preventive treatment (e.g., it will drop from 8% to 4%). Call her Woman C and assume that she is just like Woman A described in Table 1, except that Woman C cares about having average-or-below-average risk for breast cancer. Because of this preference, the utilities for various outcomes for Woman C may be slightly different than they are for Woman A.

For instance, if Woman C does not take the pill, then the utility of the outcome of *not having breast cancer* may be slightly lower than 1, since even though she has avoided breast cancer, she has to live with above average risk, which has negative utility for her. If Woman C does take the pill, then the utilities of all the outcomes under this choice on Table 1 ("Decision = Take the Pill") may be slightly higher for her than for Woman A, since in all these cases Woman C lives for at least some time with below average risk, which has positive utility for her. These slight changes in the utilities of individual outcomes could raise the expected utility of taking the pill above that of not taking the pill. Thus, it appears that the comparative risk information could be relevant to Woman C’s decision whether to take the pill.

The discussion by Fagerlin et al. [5] and in the previous section, above, did not consider the possibility that a woman would care in this way about her risk level. Instead, these discussions focused, understandably enough, on health outcomes such as breast cancer and heart attacks. But after considering the example of Woman C, it becomes apparent that comparative risk levels may be relevant to determining the utility of outcomes for at least some individuals. Other unanticipated features of situations may be relevant as well, for instance how treatment or illness would interfere with work, or with a weekly tennis game, etc. It is basically impossible to anticipate the range of issues that may come into play in determining the utilities of possible outcomes for individuals, given the wide variety of desires and interests.

The fact that decision theory treats any interest that the individual has as being legitimate fodder for decision analysis reflects a more general philosophical approach stemming back to Hume, where a person’s rational capacities do not determine her goals but instead are used to calculate how best to pursue them [14]. It is assumed that in a free society, people will have widely varying goals and desires, and a broad range of these are considered consistent with rationality [15].

Also, there is good reason to believe that preferring to have average-or-below-average risk for breast cancer or other diseases is common in modern society. Although a person may be perfectly healthy and have increased risk at the same
time, there are important analogies between *having normal levels of risk* and *being healthy*. Health is usually defined as normalcy of some sort, often related to the presence of typical levels of functioning [16], and having average risk is a type of typicality or normality as well [17]. The details of the definition of health and disease are complex and fall beyond the scope of this paper, but there are apparent links between the importance of health and of normalizing risk [18, 19].

In the case of tamoxifen, which serves as the model for the pill described to subjects in Fagerlin et al. [5], it is relevant to note that many of the women who qualify for use of this medication for prevention of breast cancer may well harbor a dysfunction, such as a mutation in the BRCA1 or BRCA2 gene [20]. Telling a woman that she has above average risk may thus alert her to the presence of a disease or abnormality, and in this way comparative risk information may be quite relevant to her making a decision about her medical care. Admittedly, some women who have elevated risk of breast cancer and qualify for possible treatment with tamoxifen have no identifiable disease or dysfunction. For example, a woman may have elevated risk due to factors such as age, a history of early menarche or few or no pregnancies, and family members who had breast cancer [20]. But, even in this case, the desire to have “normal” risk seems not so far removed from the desire to be healthy, which is given pride of place in medical ethics and philosophy of medicine.

**Evaluating (P) and theories of rationality**

Problems with (P)

The defense of comparative risk information presented above, based on the importance that some people may place on having average-or-below-average risk, is not an entirely adequate response to the attacks. Perhaps most importantly, some people do not care whether their risk level is above or below average. For such people, the comparative risk data are irrelevant, as defined in (I).

But there are other flaws in the argument against comparative risk information, most importantly centering on principle (P). In particular, there are counterexamples to it, i.e., cases where a piece of irrelevant information can increase the chance of an individual’s making a rational decision. For example, consider a woman who *underestimates* the chance that she will get breast cancer. Even after being told that she has a 6% risk of developing this disease in the next 5 years, she acts and feels as if the chance is lower. In this case, telling the woman that her risk is *above average* may increase her concern about the possibility of getting breast cancer and thus may help to bring her risk perception into closer correlation with reality. Therefore, giving her comparative risk information may make her more likely to act in keeping with expected utility theory.7

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7 I am thankful to an anonymous reviewer for suggesting the following case, where comparative risk information may also improve decision-making. Consider a woman with above average risk who is reluctant to undergo treatment with tamoxifen since she doesn’t know anybody else who is taking the medication. In this case, telling her that her risk is above average may help counteract her reluctance—which is irrational on the basis of expected utility theory—by explaining why she is different from other women she knows.
Similarly, consider a woman who generally overestimates her risk, even after hearing that her personal risk is 6%. If her risk level is below average, then telling her this—providing comparative risk information—may lead her to form a more accurate assessment of her risk and lead her to make a decision that is more closely in line with expected utility theory.

Admittedly, there are other situations where comparative risk information can decrease the accuracy of risk perception, such as when a woman who overestimates her risk is told that her risk is above average, or when a woman who underestimates her risk is told that her risk is below average.

Only empirical research can determine which situations are more common, i.e., ones where comparative risk will improve accuracy or worsen it. There are multiple factors that may lead a person to overestimate or underestimate her risk, even after he or she is given personal risk information. Research into the optimism bias, for instance, shows that many people have a tendency to underestimate the chance of an undesirable event that they may undergo [21, 22]. In contrast, Tversky and Kahneman [9] describe settings in which individuals have a tendency to overestimate the chance of rare events. There is evidence that many women overestimate their risk of breast cancer, perhaps due to the large amount of reporting about the disease and public health messages encouraging women to get mammograms [23].

Again, only further research can determine whether patients considering preventive treatments of various sorts have accurate ideas regarding their baseline risk, and whether providing comparative risk information improves or worsens their decision making, considered in light of expected utility theory. Still, since it possible that comparative risk information will help some women make better decisions, principle (P) is false. And thus, even for decision analyses where comparative risk information is irrelevant—as for women who do not care about their risk levels, per se—one cannot be certain that such information should not be given.

Accounts of rationality

A supporter of the argument against comparative risk information might respond that even if such information were to improve the accuracy of a woman’s perception of her risk, and thus were to increase the chance that she will choose an action favored by expected utility theory, it would not, by so doing, increase the rationality of her decision. Thus, such a supporter could argue, the hypothetical case should not be taken as a counterexample to (P).

Evaluating this response requires assessing whether the rationality of a decision is determined by the process of decision-making or the outcome [10, 24]. In short, the defense of (P) considered here depends on seeing rationality as based on an evaluation of the process, where a fully rational decision is one where the individual understands the relevant outcomes, probabilities, and utilities, and then uses them to calculate and maximize expected utility. The “Standard Picture,” as some theorists have dubbed this approach, sees a rational decision as one made “in accordance with principles of reasoning that are based on rules of logic, probability theory and
so forth” [25, p. 4]. Someone who is committed to the Standard Picture could argue that a woman who overestimates her personal risk, and then is reassured (for no good reason) by her comparative risk, is not acting in accordance with central “principles of reasoning.”

But this defense of (P) has two major weaknesses. First, it is not clear that using comparative risk information to correct a misperception concerning risk is truly a deviation from principles of reasoning. Perhaps the influence of this information should be seen as helping the individual form an accurate assessment of her risk, and thus as helping her make a decision in keeping with the Standard Picture. Perhaps the information improves her perception, and she then reasons correctly based on it.

Second, problems with the Standard Picture weaken this defense of (P). Research has shown that humans perceive risk and choose actions in ways that rarely conform to the strict standards assumed by the Standard Picture [10, 24]. As mentioned in the discussion of the dual representation model above, individuals appear to make decisions partly based on their general sense of the significance of the risk, separate from any quantitative representation of its magnitude [3, 5, 7]. In addition, evidence concerning heuristics and biases of human thought and evolutionary psychology suggest that people reason in a variety of ways that do not match the Standard Picture [10, 24].

For these reasons, many theorists have adopted a model of rationality that focuses on the outcomes of decision-making rather than the process. According to the “consequentialist” or “pragmatic” approach, “what it is for a reasoning process to be a good one is for it to be an efficient means of attaining the pragmatic objective of satisfying one’s personal goals and desires” [10, p. 40]. From such a perspective, analyses of expected utility may be useful in determining the best choice for an individual, in some sense, but any process for reliably arriving at that choice will count as rational [13, pp. 53–59]. And from the perspective of the pragmatic approach, if comparative risk information can reliably improve the success of individuals at maximizing their expected utility, then the information can form a key part of rational decision-making.

One of the strongest arguments supporting the pragmatic approach to rationality is that there is no clear benefit to reasoning according to any strict standards—such as those assumed by the Standard Picture—if there is a different process that can just as reliably guide the individual to choices that will maximize utility [10]. In addition, given the limited amount of time available in many situations and the finite amount of human brainpower, utilizing “fast, frugal algorithms” may be rationally advisable [26]. It seems very possible that comparative risk information could play a role in such a heuristic for decisions about preventive measures.

An alternative to (P)

For the remainder of this paper, I will adopt the pragmatic definition of rationality. But once we adopt this definition, the argument against comparative risk information can be regenerated utilizing a principle that is closely related to (P). The relevant principle is the following (with the changes from (P) in italics):
(P') Irrelevant information (as defined in (I)) will not reliably improve, and will often interfere with, the rationality of an individual’s decision.

As described above, although there are hypothetical situations where comparative risk information will increase the accuracy of a person’s risk perception, there are also many where the information will reduce accuracy. Thus, one might adopt (P’) and conclude that comparative risk information should not be given. From this perspective, until empirical research can disprove (P’), the prudent option is to avoid giving comparative risk data.

A major problem with this form of the argument is that it relies on the assumption that information should be withheld if its overall impact is unknown. One could argue just as easily that even if (P’) is true, as long as there is no proof that a type of information will always interfere with patients’ making rational decisions, then it should be provided. As Fagerlin et al. write, women ask whether their risk is above or below average and most subjects in their experiment rated the comparative risk data as being helpful [5]. Given this eagerness, uncertainty about the effect of the information seems to favor providing it rather than withholding it.

Remember as well that psychological research suggests that even if comparative risk information is not explicitly provided, individuals still utilize unstated comparisons to form an intuitive sense of the seriousness of the risk they face [3]. So a personal risk of 6% may sound high to one person and low to another, for all sorts of reasons, including their beliefs about typical risk or even their previous assumptions about their own risk [27]. Providing explicit comparative risk information does not introduce a new factor into risk perception, and may even correct misperceptions.

**Conclusion: the purpose of disclosure**

Closely examining the argument against comparative risk information demonstrates how difficult it is to arrive at any firm conclusions about whether a certain type of information will help or hinder rational decision-making. And the discussion shows that even if a piece of information will mislead or confuse some people, it is not a simple matter to conclude that the information should not be given. Perhaps it is enough that it will help selected individuals, or that patients generally want the information and will feel uncomfortable if it is withheld. In short, there are complex questions to consider regarding the purpose of disclosure and the ethical principles regarding patient choice.

The discussion also highlights the difficulty of determining if a specific decision is rational or not in light of expected utility theory. A patient’s decision to take tamoxifen, for example, could be due to a calculation that this will maximize her expected utility, as for woman B in Table 1. But, alternatively, it may be that taking the pill does not maximize her expected utility—e.g., if her utilities resemble those of woman A in Table 1—and she is miscalculating in one way or another. The woman may be overestimating her chance of developing breast cancer, as in the cases considered above (Section “Problems with (P)”), or she may be making other
possible mistakes. For instance, the patient may be underestimating the utility of life with breast cancer (i.e., overestimating the impact), such as by failing to recognize the large percentage of patients who are treated conservatively and/or cured. Alternatively, the patient could be underestimating the frequency of having one of the side effects of tamoxifen, or overestimating the severity of those side effects (and underestimating, therefore, the expected utility of taking the medication).

Given all these possibilities, it is exceedingly difficult to know for any given patient whether or not he is making a decision that maximizes his expected utility. It is important to note as well that doctors generally do not carry out such fine-grained evaluations of their patients’ decisions. In fact, healthcare providers often do not even assess their patients’ understanding of basic information, much less examine whether the decision fits with their values or goals [28]. Anecdotal information suggests that a patient’s decision is challenged only when it appears to violate his best interests, as when an individual turns down a non-burdensome life-saving treatment.

It may be that healthcare providers are aiming to help their patients maximize expected utility but are operating within informational or pragmatic constraints. Alternatively, providers may be applying a different theory of rationality, such as one that does not require maximizing expected utility but just satisficing, i.e., finding an outcome that is “good enough” [29]. Such theories of bounded rationality resemble the pragmatic or consequentialist approaches discussed above by emphasizing that real-life decisions are made based on limited information, using finite brain power, in an environment where “fast, frugal, heuristics” may be very helpful [26, 30]. If a theory of bounded rationality were assumed, the argument against providing comparative risk information would be weak, since these theories make no assumption that formally irrelevant information is not helpful to good decisions. Also, a satisficing account of decision-making could conclude that the decision to take tamoxifen or reject it may both be equally rational for a given patient, if both choices are “good enough.”

Finally, it may be that healthcare providers are not oriented primarily towards promoting rational decisions and that accounts of patient decision-making should not assume that this is the goal of disclosure and informed consent. A number of writers have questioned the assumption that patients always want or need information that will allow them to make an “autonomous” decision [31, 32], and some have proposed that the doctor-patient interaction should be interpreted instead in terms of speech acts such as asking permission or showing respect [33]. For such approaches, the evaluation of whether to give comparative risk information, and in what settings, involves very different considerations than those raised by Fagerlin et al. [5].

In the end, the discussion highlights the complex issues that must be considered in deciding what information to provide to patients concerning available preventive tests or treatments [34]. And decisions of this sort are becoming increasingly important, with medicine’s growing focus on prevention and with progress in genetics and epidemiology promising to make much more detailed risk information available to patients and providers in the future. Clarifying the goals of disclosing
information in preventive settings, and then finding ways to achieve these goals, will be a central task of medicine and medical ethics in the coming years.

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