The Right Tool is What They Need, Not What We Have: A Taxonomy of Appropriate Levels of Precision In Patient Risk Communication

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Running head: Taxonomy of Precision in Risk Communication

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Abstract

While patients often receive risk information, exactly what constitutes being "informed" about health risks is often unclear. Patients have specific needs, such as avoiding being surprised by a possible outcome and making complex risk tradeoff decisions. Yet, all risk information is not equally informative for those needs. In this paper, I present a taxonomy of seven risk concepts that vary in their inherent precision and evaluability. Congruent with the "less is more" concept, I argue that risk communications should use formats that are tailored to message recipients' specific informational needs. Simpler formats can be used when patients only need to order risks, while more complex numerical probability statements will be necessary when patients need to assess differences in risk magnitude and put those differences into meaningful context. Selecting need-congruent formats when designing communications about risks to patients is a novel approach that may better support patients' healthcare decision making.

Introduction

The header on the web page says, "Calculate your heart disease risk score!"

Knowing what our risk is. A simple concept, in principle, and one many patients think about. However, the important, yet often unasked, question is: What does it mean to actually "know" your risk?

Imagine a patient, Robert, who goes to a website that offers a heart disease risk calculator. He answers questions about his age, weight, cholesterol test results, and blood pressure levels. The site then gives Robert a risk estimate: "Your 10-year risk of cardiovascular disease is 14.523%." It might show a graphic. He prints out a copy for his records. Later, he's talking with a friend about the calculator. Robert shows his results, and says:

"So, I used this calculator, and it told me what my risk is. But, I'm still confused. Am I at high risk or not? What am I supposed to do with this number?"

There are a couple of problems with Robert's story. First, it is highly unlikely that a risk calculator that used a limited set of patient responses can, in fact, calculate Robert's cardiovascular risk to a thousandth of a percent. Such excess precision conveys an artificial sense of model precision and also impedes comprehension and trust in the risk estimate itself. (Witteman, Zikmund-Fisher, Waters, Gavaruzzi, & Fagerlin, 2011)

More importantly, while Robert was in one sense fully "informed" of his cardiovascular risk, the information did not address his motivation for learning about his risk: He wanted to know whether it was "high" or "low," a classification that might help him decide, for example, whether he needs to see his doctor. Instead of answering that question, the calculator provided information that ostensibly offered a more precise measure of risk than Robert wanted and than was needed to motivate him to potentially change his behavior. This anecdote illustrates the fact that while patients have specific needs that can be addressed by appropriate risk information, all risk information is not equally informative to specific patient needs.

New Contribution

In this paper, I present a taxonomy of seven distinct risk concepts that vary in their precision and also in their evaluability, a term which refers to whether a piece of information is easy or hard to interpret as good or bad; and hence whether it is more or less likely to be meaningful in decision making (Hsee, 1996; Hsee, Blount, Loewenstein, & Bazerman, 1999). What it means for a patient to accept a risk message and to integrate it into his or her self-identity is different at each conceptual level. Based on this taxonomy, I discuss several examples of medical risk communications and argue that the optimal format for each use should be congruent with patients' specific informational needs.

A Taxonomy of Precision and Evaluability in Risk Constructs

Informing patients about health risks should start by acknowledging that risk information comes in many forms, each differing in the relative precision of meaning that patients can derive from them. Table 1 summarizes seven conceptual levels of risk information in a rough taxonomy, which can be divided into two groups: *possibility* statements, which are non-numeric, and *probability* statements, which can be presented quantitatively and graphically in a number of ways.

Possibility statements communicate that someone is at risk. Robert could get cardiovascular disease (and hence he is not "safe"), yet disease is not certain to occur. Statements such as "it might happen, and it might not" represent this idea. Many people use the phrase "a fifty/fifty

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chance" to mean only possibility rather than a specific likelihood,(Bruine de Bruin, Fischhoff, Millstein, & Halpern-Felsher, 2000) and most people are more sensitive to changes from certainty to uncertainty than changes in the degree of uncertainty (Kahneman & Tversky, 1979). In fact, people sometimes avoid treatment options with lower mortality risks simply because they do not want to deal, in a psychological sense, with any possibility of even rare side effects (Amsterlaw, Zikmund-Fisher, Fagerlin, & Ubel, 2006).

Possibility statements can vary in their meaning. *Relative possibility* is a purely ordinal concept: it clarifies that one outcome is higher or lower than an established standard outcome (e.g., Robert might learn that his risk is "higher than average"). Similarly, *comparative possibility* is the term used in this paper for relative possibility statements across groups or dimensions, such as Robert learning that he "is more likely to get cardiovascular disease than colon cancer." Both relative and comparative possibility statements are vague in precision, yet are highly evaluable (i.e., inherently meaningful) and yield clear affective gist meanings – "I have a worse risk" is bad without any additional information. Such statements are sufficient for many tasks, such as recognizing a less risky treatment option or identifying the most common side effect.

Categorical possibility describes information that places a person's risk in a predefined category (e.g., "elevated"), which is what Robert was looking for but did not receive from the risk calculator. Examples include a prenatal screening test that clarifies that a woman has a "normal" risk of having a Downs Syndrome child, and a middle-aged man whose cholesterol and blood pressure imply a "borderline high" risk of a heart attack. Whether categories like these are meaningful for patient decision making, including through the evocation of emotions (Peters, Lipkus, & Diefenbach, 2006; Slovic & Peters, 2006), depends on the terms used. Category labels such as “poor” or “dangerous” convey clear good versus bad meanings (Peters et al., 2009), while more comparative terms (e.g., “high risk”) require additional knowledge before gist meanings can become clear.

Probability statements differ from possibility statements in that they involve numerical risk estimates. The most commonly used formats are *relative probability* statements (e.g., Robert being told he is at 50% more risk because he smokes), which are precise in ratio but omit risk level information, and statements, however accurate and grounded in good science and sound statistical estimates that include all relevant influencing factors, of *absolute probability* (e.g., Robert’s 14.523% risk). Such statements can vary in numerical precision (i.e., 12.3% vs. 12%) and estimate precision (e.g., because of varying data sample sizes), and they may be structured as either percentages or frequencies (e.g., 12 out of 100). As discussed below, these formats are particularly hard to evaluate.

Comparative probability statements are used to denote presentations of multiple absolute probabilities that facilitate inter-group comparisons, thereby increasing evaluability. In Robert’s case, he might compare his current risk with an estimate of his risk if he quit smoking. While a single probability can be good or bad depending on context (Zikmund-Fisher, Fagerlin, & Ubel, 2004), multiple probability statements automatically provide reference standards for each other, thereby clarifying order and helping to define people’s more meaning-laden affective perceptions in addition to their more cognitive assessments of objective probability (Windschitl, Martin, & Flugstad, 2002). The effective precision of such statements is also greater than either relative or absolute probability statements because level and ratio information are simultaneously available.

The last risk concept is *incremental probability*, often described as the absolute risk reduction or increase. When presented alongside a baseline risk level, incremental probability statements

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directly describe changes in risk. For example, Robert could have been told that his risk would be 8% if he were a non-smoker, but he has a 6.5% greater chance of cardiovascular disease because he smokes. Incremental presentations can reduce worry about side effect risks (Zikmund-Fisher, Fagerlin, Roberts, Derry, & Ubel, 2008), most likely because they clarify how much risk will exist regardless of the patient's treatment choices. While one can subtract comparative probability statements to calculate incremental probability, incremental probability statements are simpler and hence more evaluable for risk differences. Such statements are precise to whatever degree stated (in terms of decimal places) and/or modeled (via confidence intervals).

Gist Meanings of the Seven Risk Concepts

According to Reyna's Fuzzy Trace Theory, risk information is encoded in both verbatim and gist-level forms, with greater reliance on gist in decision making (Reyna, 2004), especially as people age (Reyna, 2011). Each of the seven risk concepts outlined above differ in the gist meaning that patients may remember from hearing or reading them. To illustrate this, the last two columns of Table 1 present illustrative statements that a patient like Robert might make upon accepting risk information at each level, as well as the types of emotional meanings he might take away from that knowledge.

Note that acceptance of risk messages does not depend on accepting risk as a measurable quantity. Statements such as "it could happen to me" do not convey much precision, but they identify someone who understands that uncertainty exists. More complex probability statements, such as "my risk will change this much if I do this," require people to conceive of their "risk" as something tangible and measurable and then to change their self-identity to be congruent with the statistical information.

The varying personal meanings of risk concepts define the standards we should use to determine whether a patient is "fully informed" about a risk. Ensuring that a patient knows that they are at risk requires only possibility acceptance. Categorical risk knowledge requires accepting the category label into one's self-identity. Understanding absolute risk requires comprehending the statistical concept of probability and the specific ratio implied by the data, though such knowledge is not always useful for decision making. Absolute risk statistics will not convey categorical possibility knowledge unless patients like Robert have the background knowledge (or comparative risk statistics) to make them affectively meaningful. Furthermore, even when meaningful, a single absolute probability may be insufficient to "inform" a patient if precise understandings of risk changes are essential for decision making.

For example, women asked to provide numerical likelihood judgments of breast cancer risk often "overestimate" their risk by providing numbers above population prevalence rates (Fagerlin, Zikmund-Fisher, & Ubel, 2005; Lipkus, Biradavolu, Fenn, Keller, & Rimer, 2001; Woloshin, Schwartz, Black, & Welch, 1999). These same women could be accurate at the relative or categorical possibility level by identifying themselves as "average risk." Unfortunately, when women with a greater than 1.7% 5-year risk of developing breast cancer were given a breast cancer prophylaxis decision aid that presented absolute and comparative probability information, most thought they were at average or low risk even though they all met the clinical criterion for being "high risk" (Dillard et al., 2011). Such categorical possibility errors are far more concerning than are numerical overestimates of absolute likelihood.

Defining Appropriate Precision

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Considered on the basis of usefulness, the levels of risk discussed above seem to correspond to different tasks that patients face. Table 2 outlines several common patient needs and the types of risk knowledge that seem most congruent to those needs.

First and foremost, risk information helps patients become aware of when they are at risk. Such awareness helps patients to avoid being surprised by unanticipated outcomes (e.g., important complications of medical procedures, such as impotence risks of prostate cancer surgery), thereby minimizing avoidable decision regret. Patients in such situations care most of all that they understand that something might happen, and hence possibility statements are the simplest method for accomplishing that goal. Numerical probability statements (e.g., 30% chance) require complex thought, and patients provided with numbers might think more about what the number is than that the risk might occur.

Another basic need is knowing when a treatment option is dominant (i.e., provides the same benefit with fewer risks or larger benefits with equal risks). For example, a birth control pill formula that is equally effective at preventing pregnancy but has lower side effect rates is a dominant option. Comparisons of new versus old therapies sometimes have this characteristic, as can targeted versus broader interventions. Here again, specific risk levels are unnecessary; relative possibility knowledge is all that is needed.

A different patient need is to become motivated to act to reduce risks. For example, Robert might estimate his risk of cardiovascular disease from an online calculator, discuss the risks of smoking with his clinician, or have his home tested to determine the level of radioactive radon gas present. In all of these cases, Robert wants the risk information he receives from these communications either to clearly signal that he needs to take action to reduce risk or to provide reassurance that immediate action is not required. Patients in these situations care about categorizing themselves, and thus categorical possibility information is optimally useful. While numerical detail about risk levels or relative risk ratios provides greater precision (e.g., by identifying borderline cases), the effort required to translate such statistics into categories typically impedes the usefulness of such statistics in addressing the primary need.

The most common type of medical decision is a multi-risk tradeoff choice in which alternatives are comparatively better on some risks and worse on others. Examples include many shared decision making situations, such as prostate cancer treatment decisions and decisions about surgeries for lower back pain. Here, what patients care about is (a) understanding that tradeoffs exist, and (b) clarifying which risks are more important to them. Such needs can be met by comparative probability statements (e.g., "12% of women taking tamoxifen develop cataracts, as compared to 10% of similar women who do not take it"). However, the precision inherent in comparative probability data may be unnecessary if patients simply need to know that they have a high chance of one outcome versus a low chance of another. In such cases, comparative possibility statements (e.g., "prostate cancer surgery results in lower rates of anxiety but higher rates of impotence and incontinence than does active surveillance") are likely sufficient.

Patients do need precise numerical risk information for what might be termed magnitude-dependent risk decisions. An example can be seen in this author's studies of women's decisions about adjuvant therapy options to reduce future cancer recurrence risk. These therapies vary in their side effects and burden, and therefore patients must have a precise understanding of the magnitude of benefit achievable to make such choices–simply knowing the benefit is more or less is not sufficient to support decision making. Precise incremental probability information is required, as shown by recent studies that have demonstrated that making the incremental benefit easier to identify and understand improves the decision making, especially among patients with lower numeracy (Zikmund-Fisher, Angott, & Ubel, 2011; Zikmund-Fisher, Fagerlin, & Ubel, 2008).

The Comparative Irrelevance of Relative and Absolute Probability Statements

Simple risk concepts such as relative possibility and comparative possibility have clear advantages: they can provide meaningful guidance for behavior but do not require precision on the part either of the communicator or the patient. As such, they are examples of the "less is more" concept that has been shown to improve understanding and decision making, especially among the less numerate (Peters, Dieckmann, Dixon, Hibbard, & Mertz, 2007; Zikmund-Fisher, Fagerlin, & Ubel, 2010). It should be noted that when decisions require evaluations of marginal risk changes or magnitude-dependent tradeoffs between different risks, comparative and/or incremental probability statements are likely to be required.

Statements of relative and absolute probability, however, seem overshadowed in this hierarchy because (to borrow from *Annie Get Your Gun*) "anything [they] can do, [other formats] can do better!" While relative probability statements clarify higher versus lower risks, relative possibility statements accomplish the same goal without unnecessary precision. If difference magnitude is important, comparative probability statements convey the same information as relative risk statements but add risk level information for context. Doing so helps to prevent the known tendency of relative risk statements to bias risk perceptions (Baron, 1997; Fahey, Griffiths, & Peters, 1995; Naylor, Chen, & Strauss, 1992). For example, an increase in risk described only as "50% larger risk" can evoke strong reactions even if the change is only from 2% to 3%.

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Similarly, absolute probability statements are overkill if the primary risk message is mere possibility (e.g., vaccinations can result in temporary soreness), and they omit the meanings associated with categorical possibility statements (e.g., Robert learning that he is at "high" risk of cardiovascular disease). Furthermore, people's difficulty in evaluating single probabilities when presented in isolation means that comparative or incremental probability statements are almost always preferable when precision in risk knowledge is required. For example, stating that 12% of patients who take a drug experience headaches is fundamentally insufficient because it leaves unstated the baseline rate of headaches in an untreated population. It is clearly appropriate for a patient to be more concerned about this drug if the baseline risk of headaches is 2% versus 8%. Incremental probability statements (e.g., "4 more patients out of 100 experience headaches because of taking the drug") solve this problem by specifying how much risk is intervention-related. Alternately, one can improve evaluability by using comparative probability statements (e.g., "…versus 8% of patients in a control group"), which explicitly define the standard of comparison but leave the patient to do the math required needed to figure out the incremental risk.

The Right Tool is What They Need, Not What We Have

The above leads to a simple conclusion: Risk communicators must identify *why* patients need risk information before they can consider what form of risk communication to provide.

Clinical trials in medicine and epidemiological studies in public health each generate volumes of risk estimates, usually in the form of absolute probability or relative probability statistics. Yet, just because such data exist does not mean that communication of risk statistics will be useful to patients. It is always the communicator's responsibility to know why he or she is providing information to a message recipient. In a clinical context, for example, this principle implies that clinicians should have a clear sense at any given moment whether their patient most needs awareness of the

- possibility of risk;
- motivation to change that risk;
- comparative information to enable consideration of this risk versus others; or
- precise estimates of how this risk would change in different situations (e.g., pre- versus post-intervention).

The fact that patients may have all of these needs at different points in time does not alter the communicator's responsibility to have a specific purpose at the time of communication.

Unfortunately, even when risk data could meet specific information needs of patients, health professionals often assume that providing such statistics to patients in their original format is equivalent to informing them. This is a "curse of knowledge" problem (Heath & Heath, 2007). Because precise statistics convey multiple meanings to clinicians and researchers (because of their expertise and background knowledge), they cannot imagine that the same risk formats will not be equally meaningful for patients.

The risk concepts discussed above suggest that clinicians and educators should have clear goals for their risk communications (based on specific patient decision-making needs, such as those listed in Table 2) and then use the least complicated risk formats that are nonetheless congruent with what patients actually care about in that moment. Patients, like Robert, can have goals that do not require them to receive precise, quantitative risk estimates. If all that patients want to know is

- if one treatment is better than another treatment;

- if they should act to reduce their risks; or
- when they are at risk and when they are safe,

then providing detail about these risks is likely to be counterproductive. If Robert is only seeking to classify himself in terms of risk categories, providing numerical risk estimates forces him to do mental arithmetic to derive the answer he seeks. Worse, if he lacks numeracy skills and fails to do the arithmetic properly, he may reach a conclusion that is not in his best interest.

By way of clarification, this is *not* to advocate withholding of detailed probability information from patients who request it. Some patients are sufficiently numerate and motivated to desire, for example, comparative probability statements in situations in which their decision making could be effectively informed by mere relative possibility statements. Even when detail is perhaps unnecessary, there is little harm in providing detailed statistics in a supplementary fact sheet or hyperlinked resource. Nevertheless, the primacy of gist-level processing in decision making (Reyna, 2004) suggests that separating detail from gist-focused messages is often important. Less numerate people often have difficulty separating decision-critical gist information from extraneous information (Peters et al., 2007). Furthermore, even highly numerate people do not always want or need every piece of information they could have.

Evidence to support the use of simpler, less precise communications of risk over more detailed data formats can also be found in the competitive marketplace for information designed to help consumers make good decisions. Look, for example, at Consumer Reports, one of the most widely read sources of risk information (e.g., the risk of an automobile problem). Consumer Reports knows that consumers need to recognize when one car is consistently riskier than another one (relative possibility) and when a model can be characterized as being "reliable" (categorical possibility). Consumers also need to make gist-level tradeoffs between cars that are better on some dimensions and worse on others (comparative possibility). How does Consumer Reports meet those needs? In general, it does not present probabilities. Instead, it presents simplified tables of icons that categorize cars into one of five risk groupings for each automotive system, facilitating categorical comparisons across both systems and models. In other words, it intentionally communicates gist-focused messages at the cost of more detail.

Risk communication is an inherently hard task. The concept of probability is unintuitive and intangible, which is why clarification of possibility is a non-trivial risk communication. Patients don't experience likelihood, and nor do they experience population-level rates. They experience single outcomes—something happens or it does not happen. Perhaps Kurzon captured the essence of risk communication best when he described learning about his own likelihood of surviving cancer as coming to understand "how predictable it is to be as lucky as I am" (Kurzon, 2004, p. 12). Furthermore, to truly understand their health risks and make informed decisions, patients also need to understand why they are at risk and the relationships between risk factors and disease risk (Downs & Fischhoff, 2011). Just as comparative data about other risks helps patients derive meaning from their own risk data, qualitative risk communications that inform patients' mental models of risk can make risk data intuitive and credible, laying the foundation for both value-congruent decision making and motivated health behavior change.

To help patients like Robert understand the personal meaning of risk messages, we should endeavor to communicate about risk likelihoods using formats that align with patients' decision-making needs. Precise, detailed risk statistics may be required for certain complex decisions, but simpler, less precise representations will often be more useful. Clinicians, educators, and public health officials must recognize the correct risk number is not always the best risk message. Instead, it is our job to give patients, if I may borrow the phrase, "the right tool at the right time."

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Table 1. A Taxonomy of Risk Concepts

Risk Concept	**Sample Cognition**	**Distinguishable From**	**Level of Precision**	**Evaluability**	**Illustrative Gist Statements**	**Illustrative Emotional Meanings**
Possibility	Might happen, might not	Will / Won't	Minimal	Very High	"It could happen to me."	"I am at risk." *(Implies negative feelings if for a bad outcome)*
Relative / Comparative Possibility	More likely	Less likely / Equally likely	Vague	High	• "It is more likely to happen to me than to others." • "I am more likely to have this happen to me than to have that happen to me."	• "I have a worse risk than others." • "I have a worse risk of this than that."
Categorical Possibility	High chance	Normal / Average	Defined by categories	Depends on categories	"I am a person who has a high chance of this happening."	"I have a bad risk."
Relative Probability	50% more likely	Other ratios, e.g., 40% more likely	Ratio only	High for ratio, low for meaning	"I have a risk that is higher to this degree."	"I have a worse risk than others."
Absolute Probability	12%	Other probabilities, e.g., 13%	Level	Low	"My risk is this."	*Unclear without background knowledge*
Comparative Probability	12% vs. 8%	Other combinations, e.g., 15% vs. 10%, 12% vs. 11%	Level, with Ratio by calculation	High	• "My (group's) risk is this, which is higher than another's (group's) risk." • "My risk is this if I do X, which is higher than my risk if I do Y which is that."	• "My risk is worse than their risk is." • "My risk is bad and worse if I do X."
Incremental Probability	4% more likely	Other increments, e.g., 5% more likely	Change in Level	High for difference	"My risk will change that much if I do this."	"My risk will change a lot (or a little)." *(Affect depends on comparison to baseline)*

Accepted version. Final version available at: Zikmund-Fisher BJ. The right tool is what they need, not what we have: a taxonomy of appropriate levels of precision in patient risk communication. *Medical Care Research and Review* 2013;70(1 suppl):37S-49S. doi:10.1177/1077558712458541

Table 2. Sample Patient Needs and Congruent Types of Risk Information

Need	**What Patients Care About**	**Congruent Types Risk Knowledge**	**Decision Examples**
Avoid Surprise and Regret	Care that this could happen	Possibility	Informed consent for rare treatment complications
Recognize Dominant Options	Care that this is most / least	Relative / Comparative Possibility	Choosing between medications of the same class
Motivate to Act or Not Act	Care that this is good / bad	Categorical Possibility	Risk calculators
Make Multi-Attribute Tradeoff Decisions	Care about this more than that	Comparative Possibility and/or Probability	Preference-sensitive treatment decisions (e.g., surgery vs. radiation vs. watchful waiting)
Make Magnitude-Dependent Decisions	Care that this is X% not Y%	Precise Comparative or Incremental Probabilities	Risk-reducing therapy decisions (e.g., adjuvant therapies)

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