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ESSENTIALS

What is my risk, doctor? How to convey disease risk and treatment effects

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What you need to know

- Relative effects of treatments are often described in patient encounters, scientific journals, and mass media, although used alone to guide decision making they are insufficient and potentially misleading
- Absolute treatment effects together with the absolute risk of disease one wants to prevent or treat are more informative and should be used instead
- Discussions about action thresholds for absolute disease risk and absolute treatment effects are important in patient encounters and elsewhere in the healthcare system

Ms Olsen is a 65 year old woman with hypercholesterolaemia and hypertension. Her doctor tells her that she can reduce her risk of getting a major cardiovascular event by up to 50% if she takes a statin. "That's great," she thinks, "50% reduction is a lot!" She feels happy and well informed and plans to take the statin.

After she comes home, she remembers her recent conversation with a car dealer (she really needed a new car). He told her a car he had in his lot was reduced in price by 15%. May be a good deal, she thought, and asked for the price of the car. Unfortunately it was far too high, even with the 15% off. She thought the dealer had not been honest since he did not tell her the price upfront, only the discount.

Risk for disease and for treatment effects is conveyed in many ways: relative or absolute, in percentages, hazards, or odds ratios. Some are more informative than others, and many of the most frequently used are hard to understand. This article outlines how to convey benefits, harms, and burden of interventions to patients and society in an informative way, and offers pointers for communicating absolute and relative risks in consultation with patients, colleagues, and policy makers.

Trust and shared decision making

Trust in doctors and health professionals is fundamental for informative patient encounters and subsequent patient adherence to treatment and care.[1] Patient and public trust in physicians is high, although reports have indicated a decline in recent years, with variations between countries and healthcare settings.[2] Yet, for many patient encounters in medicine, we as doctors do not provide the absolute benefits and harms of interventions we recommend. Often, we provide information only about the discount (the relative risk reduction) for the disease, and expect patients to make informed decisions, when in fact they do not have all of the relevant information to do this.[1]

As doctors we aim for shared decision making in patient encounters, so why are we making it so difficult for patients[3]? In 2012, a first year medical trainee speculated in *TheBMJ* that "many doctors are either not aware of the actual benefits of the drugs that they prescribe or do not understand the basic statistical implications of absolute versus relative risk reduction."[4] We believe the situation is similar today.

Misconception and lack of knowledge among doctors and policy makers about absolute and relative risks obstruct shared decision making and hinder truly informed consent. In our experience, use of relative risks and benefits still dominate doctor encounters with patients, as well as discussions between doctors on wards and in clinics about therapies and interventions. Most often this is not intentional, but rather unconsciously because of cultural norms around counselling patients and lack of training in interpreting and conveying risk figures.

Conveying risk and treatment effects

We believe that scientific publishing must take a fair share of blame for our suboptimal patient information about disease risks and treatment effects. Relative effect estimates such as hazard ratios, relative risks, or odds ratios have been standard in reports of observational studies and clinical trials for decades. Many scientific reports highlight relative effects,[5 6] while the underlying absolute numbers are hard to uncover, often requiring skill and time that is not at most clinicians' disposal.

In a pivotal trial of screening for colorectal cancer with sigmoidoscopy in the UK in 2017, the main outcome was reported as "colorectal cancer incidence was reduced by 26% (hazard ratio 0.74; 95% confidence interval 0.70 to 0.80; P<0.0001)."[7] The trial informed the decision to introduce population screening for colorectal cancer in the UK. While the trial reporting was not incorrect, the hazard ratio alone is insufficient as the basis of an informed decision about whether to introduce screening. In this case, the decision must take into consideration the absolute risks of colorectal cancer which the reported relative risk reduction applies to.

Media reporting on new medical interventions swiftly follows the publication of trial results, and typically conveys to the public the relative effects presented in the scientific paper. This can be appealing, as the relative effects often look more impressive than the absolute effects and attract more attention. But it

does not provide unbiased information or enable appropriate decision making. If scientific journals are obscuring the absolute risk reduction in favour of seemingly larger and more eye catching relative effects, it is understandable that the media will pick this up and present this side of the narrative.

How to communicate risk, benefit, and harm

Appropriate decision making requires discussion of outcomes relevant to the patient, and conscious communication of four features, which we outline below using the case of Ms Olsen:

1. What is the absolute risk of the disease without treatment?

For Ms Olsen with hypertension and elevated cholesterol in which statin therapy is considered; what is her risk (eg, in the next 10 or 15 years) of having a major cardiovascular event (myocardial infarction or stroke) without statins?

2. What is the benefit of the treatment in question to reduce that risk?

It may be the absolute risk difference or a relative risk reduction.

What is the reduction of risk for Ms Olsen in the next 10 or 15 years to develop a major cardiovascular event with statins, as compared with no statins?

3. What is the absolute risk of the disease with the treatment?

What is the risk for Ms Olsen in the next 10 or 15 years to develop a major cardiovascular event with statins?

4. What are the absolute risks of harms and what is the burden of the treatment?

What is the absolute risk of harms and side effects (eg, diarrhoea or muscle pain) of taking a statin for Ms Olsen in the next 10 or 15 years, and what is the burden for her to take the treatment (eg, costs, check-up appointments, downstream testing, and how statin therapy may affect her quality of life through potential fear of being at risk for disease[8])?

If one needs to choose for brevity, absolute numbers should be used because relative effects can be calculated from them, but not the other way around.

Considering absolute risks in guidelines: colorectal cancer screening

A *BMJ* Rapid Recommendations guideline aimed at improving decision making on colorectal cancer screening by applying the features above.[9] We were members of the guideline panel, which decided that the recommendations should take into account both absolute and relative risks. The panel concluded that, although a relative risk reduction by screening of about 25% as reported in the pivotal trial[7] was statistically significant, it appears small in people with a low risk for colorectal cancer. When considering the balance of benefits and harms related to the screening procedures, the panel decided not to recommend screening for individuals with a low absolute risk of disease. In a consensus process, the panel also defined any absolute risk of colorectal cancer smaller than 3% over 15 years without screening as the lower threshold for when to act at all.[8] The panel argued that in individuals with a risk lower than 3% over 15 years, the 26% relative risk reduction corresponds to an absolute risk reduction which may not outweigh the harms and burdens of screening.[8] The guideline was criticised by some experts, who argued that the relative risk reduction of 25% in colorectal cancer incidence is considerable and should encourage "increasing screening uptake and access to organised screening" without mentioning absolute risks and benefits.[10]

Patient encounter with Ms Olsen

Applying the principles above and adding numerical examples, an informative encounter for Ms Olsen would include:

- Firstly, to estimate her absolute risk of a cardiovascular event, eg, by using a 10 year risk calculator.[11] Over a 10 year period, her risk of having a heart attack or stroke is about 6%
- Secondly, to apply the expected reduction to the estimated absolute risk (6%). Let's say that the 50% reduction as suggested by her doctor is accurate (although it may be more like 20% to 25%[12]), reducing her risk by half would give her a risk difference of 3%
- Thirdly, to tell her that her risk of having a major cardiovascular event is 3% if she chooses to use a statin
- Fourthly, to inform her about the absolute frequency of side effects of statin therapy, eg, a 5% risk of muscle pain and 10% risk of digestive problems, such as constipation, diarrhoea, or bloating.

When to act on risk?

Conveying absolute risks and risk reductions instead of less informative relative numbers requires training and conscious communication. The most difficult question, however, remains: how high should a risk for a disease or condition be to act on, given a certain reduction of that risk by a therapy or treatment? Establishing thresholds for when to act is more difficult because it is sensitive to individual and societal values and preferences.

On the patient level, understanding of personal perceptions and preferences for benefits and harms of interventions to reduce a certain disease risk is important. Ms Olsen may be interested to act on a risk of 6% for a cardiovascular event, but she may not bother to take any treatment action if her risk were 3%. Other patients may see it differently and would be willing to start statins at a lower risk than Ms Olsen.

Although risk calculators for future disease are getting better and can predict individual risk quite accurately for some diseases, they still lack for many others. Collections of risk calculators and decision aids are available online for doctors and patients, such as the "Care that fits" initiative from the Mayo Clinic (http://carethatfits.org). However, some patients may agree or disagree to undergo a treatment or action regardless of the framing and facts of risk and effects, and base their decision on other factors, such as experiences of family members with the relevant disease, or financial constraints from prescription charges.[13 14]

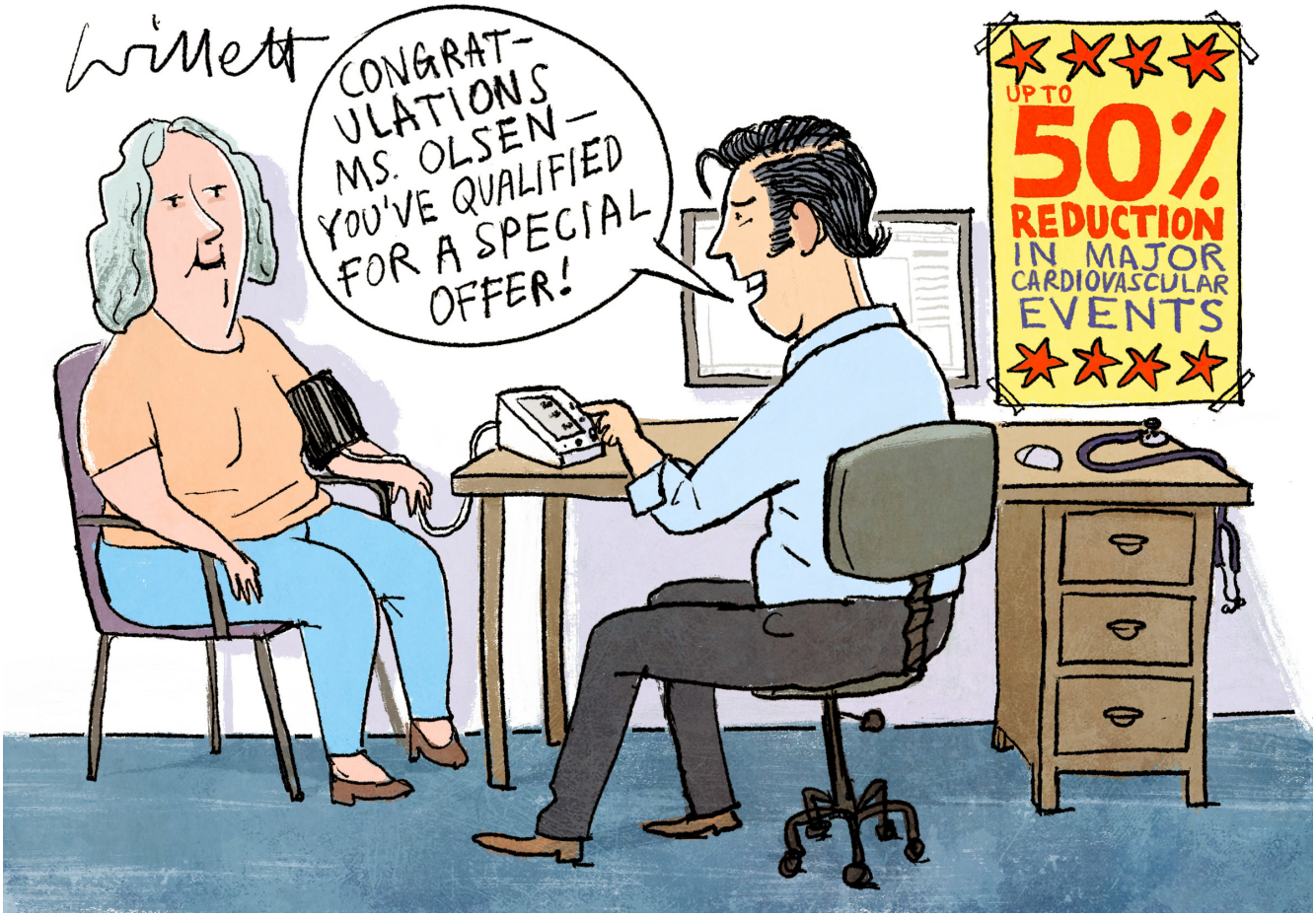
The strategy for individual patients (such as Ms Olsen) using the four described features can also be applied in decision making at a society level. Many healthcare systems provide reimbursed interventions, tests, and treatments. Most public healthcare systems also have priority guidelines and established menus of treatment options, which are offered to the population. Such priorities need to take into account absolute risk and risk reductions.

Some healthcare systems have also defined general action thresholds for interventions and treatment. In the UK, the National Institute for Health and Care Excellence (NICE) has established a threshold of £20 000 to £30 000 and uses quality adjusted life years as the measure of threshold risks and benefits.[15] Other countries, like the US, actively stay away from this difficult topic and do not include threshold discussions in clinical guidelines. Few healthcare systems, however, are rigorously using absolute risks and absolute benefits and harms in a transparent way using the features above. We believe that what is made available in a healthcare system needs scrutiny and transparent explanation using absolute risks and benefits and harms.

In our opinion, no situations in clinical medicine benefit from the use of relative *instead* of absolute differences for understanding in conversations between doctors and patients, or among doctors when discussing treatment options for a patient. In discussions of what a healthcare system should offer, use of absolute numbers is crucial to ensure equitable care. Absolute risks *and* absolute risk reductions should be used in communication with patients, colleagues, decision makers, and the media. Relative reductions may be used in addition to absolute reductions to illustrate or exemplify, but only in addition and not instead of absolute effects and risks.

Education into practice

- Train yourself to find and convey absolute risks of disease for your patient, and the absolute effects of any treatment you consider recommending
- Discuss with your patients how high a risk should be to make a certain treatment worthwhile. What factors might influence their decision?



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