

Taking risks and talking risk — from ADRs to SARS

By Prashant Sanghani

Like many readers, I found the study by Berry, Knapp and Raynor (see Table 1) about the difference between European guidelines on descriptions of incidence of drug side effects and public perception of the same descriptors simultaneously, unsurprising, worrying and thought provoking. Given that we are all trying to work with our patients towards ever-increasing joint understanding of disease and need for treatment, this gulf in perception is not acceptable. The difference between the intention by the scientists and perception by the public may lead, as the authors report, to concerns about compliance.

I believe that in addition to the ambiguities of non-numerical descriptors and general poor handling of numerical data, there are other factors that will tax us all as we try to attain concordance with our patients on treatment risks and benefits.

RANKING IN PERCENTAGES

It is possible that irrespective of the qualitative descriptors used, when asked to rank likely rates in percentage terms, the mind automatically assumes values between one and 100. After all, the typical use of percentage is to reduce absolute values to relative ones up to a tidy maximum of 100. It may be that faced with ranking five sequential descriptors as a percentage, the likely demarcations are 5, 10, 20, 40 and 80; each neatly double the last and thus just plain sensible. Of course the last value, on reflection, looks far too high to represent a side effect risk of a medicine to which the government has allowed the public access. So, a rather simple process of ranking and modest evaluation can produce the figures 5, 10, 20, 40 and 70. All of which match the findings (4, 8, 18, 45 and 65) rather well. This retrospective argument has little scientific merit and that is perhaps the point — the public do not think scientifically and so that may be the first lesson we need to learn.

I contend that humans are more comfortable with qualitative rather than numerical descriptors and that words and pictures are more memorable than figures of frequencies or percentages. This has partly been explored in the study mentioned above. Even when told that the percentage chance of a side effect occurring with a medicine was 15 per cent, the public consistently rated the chance of them suffering the side effect as higher. The authors note the need for further work in this area but to some extent, I suggest it is related to a general poor understanding of numbers, their meaning and application, along with an apparently pessimistic outlook on life. We clearly have much work ahead of us when it

comes to discussing risks and benefits of health, illness and treatment.

GOOD NEWS PLEASE

To human ears the chance of something good happening one in 100 times is far more palatable than the chance of no good occurring 99 out of 100 times — even though the scientist will discern no difference. This human bias is used to great effect by all operators of lotteries. The thought that “It could be you” who wins the jackpot continues to encourage millions to part with hard-earned cash even though the chance that it could be them is one in 13,983,816. Why do we suppose Camelot does not advertise the counterpoint — “It may not be you 13,983,815 times out of 13,983,816”? Not that this statement will alter a scientist’s likelihood of parting with his or her cash. Nonetheless, scientists, too, prefer to promote positive messages as do those involved in promoting the use of medicines.

There is a discount applied to events that are due later and this, in part helps explain the ongoing reluctance of the young to acknowledge the longer term risks of smoking. Interestingly, some salespeople are advised that using this temporal significance can help increase profits. I recall an anecdote (note the bias toward a good story) of home insulation salesmen in Scandinavian countries increasing sales by highlighting to potential customers how much money has already been lost by not installing insulation rather than stating how much could be saved next year if it was installed.

SCIENTISTS NEED HELP TOO

So far we have considered the difficulties in assessing risk that exist for lay persons and it is clear that we need to be wary of the complexity of the issue in order to begin addressing solutions of accurately communicating risks. However, this one-sided view assumes that, as scientists, we already know how best to describe risks in the first instance. This is, as we all know, not really the case. Whether describing incidence and prevalence of illness or benefits and risks of treatments, we have seen fashions change as we have moved

TABLE 1: RECOMMENDED QUALITATIVE DESCRIPTIONS WITH EUROPEAN UNION ASSIGNED FREQUENCY BANDS, AND PARTICIPANTS’ ESTIMATES (N=200)

Qualitative descriptor	EU assigned frequency	Mean (SD) frequency estimated by participants
Very common	>10%	65% (24.2)
Common	1–10%	45% (22.3)
Uncommon	0.1–1%	18% (13.3)
Rare	0.01–0.1%	8% (7.5)
Very rare	<0.01%	4% (6.7)

*Berry DC, Knapp P, Raynor DK. Provision of information about drug side effects to patients. *Lancet* 2002;358:853–4.

from P-values to confidence intervals and from relative and absolute risks to numbers needed to treat (NNTs). Indeed it is this latter format and numbers needed to harm (NNH) that suggest an acceptable method of expressing risks and benefits to the public. What, after all, could be confusing about saying that an NNT of 20 means that by treating 20 people, one person benefits?

Although NNTs may be a relatively clear means of expressing benefit, there may be difficulties in their use nonetheless. First of all there is the positive bias that scientists are prone to, as mentioned earlier. For example, we happily say to patients that following a myocardial infarction, taking a statin, beta-blocker and aspirin will reduce the chance of suffering a second heart attack. If the NNTs for these interventions (for one positive outcome in five years) are 26, 30 and 37, respectively, then the chances it could be you who benefits are 3.8 per cent, 3.3 per cent and 2.7 per cent, respectively. Or to put it in the terms of the public, “very rare” compared with placebo. Indeed, what NNT/H value would you personally find acceptable?

AND SO TO SARS

While we develop our understanding of the risk description and perception, we have today another health scare, severe acute respiratory syndrome (SARS), which most of us have discussed with patients, family and friends. We are told that the survival rate of those contracting SARS is 95 per cent. If we were to avoid percentages for the reasons outlined, would we prefer to say that 19 out of 20 survive or one in 20 die? Do these really sound the same and which would you use if you were a struggling travel operator?

Whether we are discussing risks or benefits, we have much to consider if we are to find ways to communicate effectively with the public. When it comes to attaining and maintaining concordance, we will also have to address to what degree perception is reality for patients and whether this needs altering.

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