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Risk communication: Why we need understandable information

Wolfgang Gaissmaier, Harding Center for Risk Literacy, Max Planck Institute for Human Development, Berlin, Germany

Introduction

"In this world, nothing is certain except death and taxes" Benjamin Franklin already noted in 1789, on the eve of the French Revolution. This ironic statement nicely illustrates that everything in life is laden with risk and that we are constantly at the mercy of this uncertainty. Even nowadays, however, people are uneasy about uncertainty, and many anxiously strive towards a certainty that does not exist. Yet society needs people who learn to cope with risks and deal with them in an informed way. The general lack of training to deal with risks in today's technological society has become a problem, as the following example illustrates:

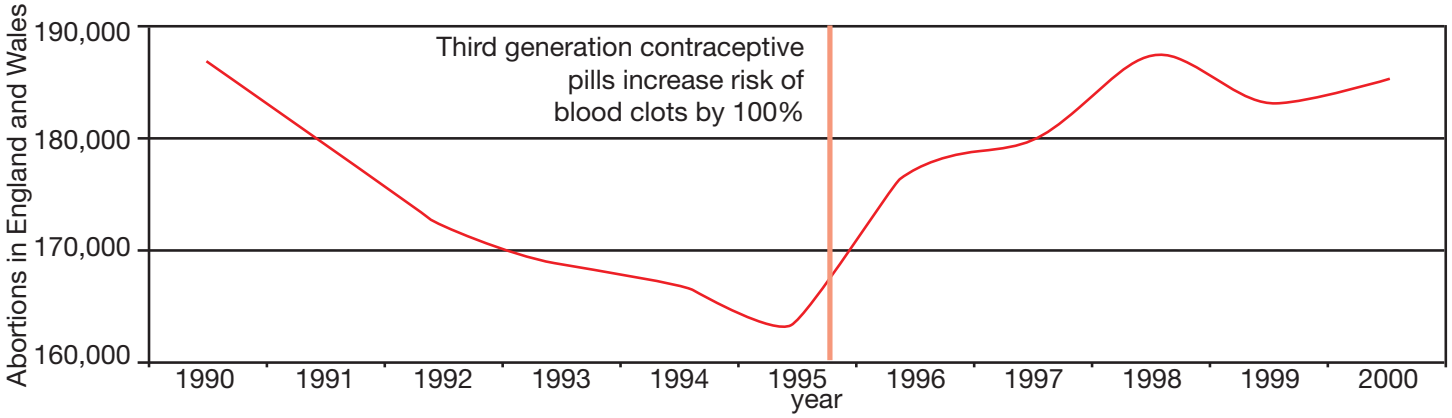
When the British press announced in October 1995 that the third generation of oral contraceptive pills increase the risk of potentially life-threatening blood clots in the legs or lungs by 100%, many women reacted with fear and decided not to take this pill anymore. This 'pill scare' led to an estimated 13,000 additional abortions in the following year, increasing the cost for the National Health Service for abortion provision by about £4 to 6 million (Figure 1)[1]. But what did the increase by 100% actually mean? The studies on which the warning was based had shown that the absolute risk had increased from one to two out of every 7,000 women.

The example illustrates a problem in the communication of statistical information about health, and this problem was already recognised a long time ago: In 1937, an editorial in the Lancet[2], one of the leading medical journals, noted about statistics that they "afford one of the few examples in which the use (or abuse) of mathematical methods tends to induce a strong emotional reaction in non-mathematical minds". It complained that for "most of us figures impinge on an educational blind spot" – even for physicians. And it still holds true today that big parts of the population have difficulties in understanding numerical information – there is collective statistical illiteracy, as a few examples in Table 1 illustrate[3].

In recent years, an effort has been made to involve patients more strongly by sharing medical decisions between physicians and patients. Yet statistical illiteracy poses a severe obstacle for shared decision making, which relies on the exchange of information between the physician and the patient and the involvement of both patient and physician in making the decision. This requires that both patients and doctors understand the benefits and harms of different treatment options. A risk communication based on misunderstandings, however, renders the "informed" in informed shared decision making obsolete[4].

Should one thus conclude that patients are not, and probably never will be, able to evaluate health benefits and risks accurately? And that, as a consequence, there is a need for a benevolent paternalism that uses methods of propaganda to persuade them to do what is considered best for them, or by nudging them to make the "right" choices[5]? Many researchers and policy makers do. I strongly disagree. Instead, we need understandable information for at least three reasons:

Figure 1. When the British press announced in October 1995 that the third generation of oral contraceptive pills increases the risk of potentially life-threatening blood clots in the legs or lungs by 100%, a reversal of the downward trend in abortions was subsequently observed (adapted from [10]).



Information can be easily understandable if it is represented well

It is premature to give up on people's ability to understand health statistics. The example of the pill scare above not only illustrates that health statistics can be severely misunderstood, but also that the representation matters. Had the absolute risk increase ("one more in 7,000") of the third generation pills been presented instead of the relative risk increase ("100%"), there probably would not have been a pill scare at all (and probably no story for the press).

Relative risks cannot only create fears. They are even more commonly used to make treatment effects look bigger. An advertisement of Lipitor, for instance, hailed the drug as cutting the risk of stroke by nearly half. In absolute terms, however, the benefits were rather small, as after four years, 2.8% of patients taking placebo had a stroke compared to 1.5% taking Lipitor.

Many studies show that people, patients as well as physicians, understand the statistical information much better when they are presented as absolute risks than as relative risks[6]. Difficulties in understanding statistical information about health should not only be looked for in our mind and our genes. Rather, the same information can either be represented in a nontransparent format to create confusion, fear or undue enthusiasm about a particular drug, or it can be transparently represented to foster insight. Numerous methods have already been developed to convey quantitative information effectively, including a variety of graphical representations[7].

Patients can have different preferences than physicians

Not involving patients in important medical decisions is also ethically unjustifiable, as it is their health that is at stake. This is particularly important as patients and physicians do not always have the same preferences, and not even the same goals.

The recent increase in cases of progressive multifocal leukoencephalopathy (PML) for people with MS who were treated with natalizumab (Tysabri) exemplified those differences. It turned out that patients would accept a higher risk of this extremely severe side effect than physicians: While only 51% of physicians would accept an event rate of more than two in 10,000, 83% of patients would do so (Figure 2)[8]. (Note that the current estimate of the actual event rate is about one in 1,000).

Many of the more cautious physicians probably had the best interest of their patients in mind, but some also may have had defensive reasons as they could be afraid to be held responsible if severe side effects occurred. At least in other medical domains, such as prostate cancer screening, it is well documented that there are many physicians who would recommend screening although they do not believe in its effectiveness, often for legal reasons[9].

Table 1.

Example questions from an assessment of basic numerical understanding on nationally representative samples in the United States of America and Germany, and the proportions who answered correctly (adapted from [3]).

	% Correct answer	
	U.S. Adults ages 25-69	German Adults ages 25-69
In the Bingo Lottery, the chance of winning a $10 prize is 1%. What is your best guess about how many people will win a $10 prize if 1,000 people each buy a single ticket for Bingo Lottery? Answer: 10 person(s) out of 1,000	58%	68%
In the Daily Times Sweepstakes, the chance of winning a car is 1 in 1,000. What percentage of tickets for the Daily Times Sweepstakes win a car? Answer: 0.1 % of tickets	24%	46%
Imagine that we flip a fair coin 1,000 times. What is your best guess about how many times the coin will come up heads in 1,000 flips? Answer: 500 times out of 1,000	73%	73%
Which of the following numbers represents the biggest risk of getting a disease? 1 in 100, 1 in 1,000, or 1 in 10? Answer: 1 in 10	75%	72%

Experts can be confused as well

Finally, patients need to be well-informed, because physicians may not understand health statistics themselves and therefore unintentionally misinform them. For instance, many gynaecologists believe that 80% or 90% of women who receive a positive mammogram in breast cancer screening actually have cancer[10]. However, the true figure is only about 10%, as most positive mammograms are false alarms.

Again, the reasons for this lack of understanding needs to be looked for in the physicians' environment. Even many of the leading medical journals, such as the BMJ, JAMA or The Lancet, report the clinical evidence in a misleading way that makes the results look more favourable. A particularly misleading way is called mismatched framing, which consists of reporting the benefits as relative risks (big numbers) and the side effects as absolute risks (small numbers)[11].

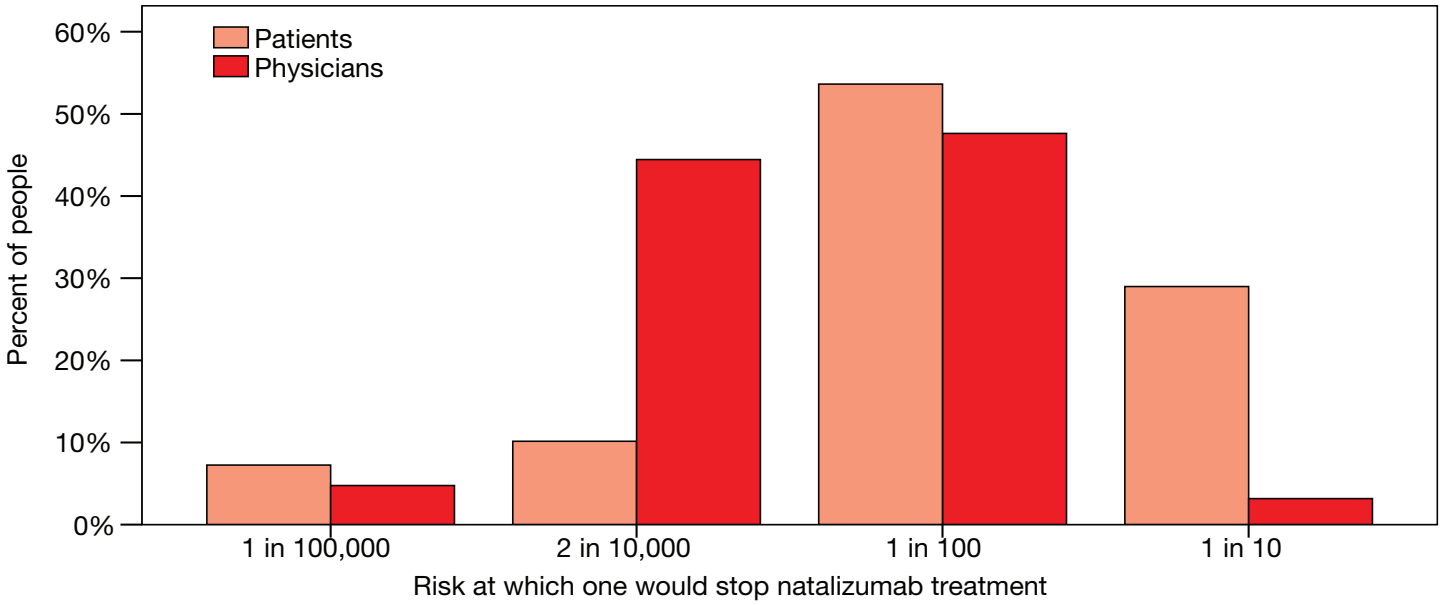
Conclusion

Already in the 1930s, HG Wells[12] predicted that for an educated citizenship in a modern democracy, statistical thinking would be as indispensable as reading and writing. At the beginning of the 21st century, nearly everyone in industrial societies has been taught reading and writing, but not statistical thinking. Many researchers present the problem of statistical illiteracy as if it were largely a consequence of cognitive limitations[13]. In contrast to this internal view, the majority of causes for statistical illiteracy discussed here can be found in the external environment, such as in nontransparent reporting of the health related information. A major remedy therefore would be to provide transparent health information based on the best available clinical evidence to the public, and Sascha Köpke and Christoph Heesen have presented excellent examples of how this can be achieved in MS in a recent issue of *Way Ahead*[14]. Additionally, the public needs to be taught how to deal with risk and uncertainty so that they are able to ask the right questions and to know when they are being misled. As Gerd Gigerenzer and Muir Gray put it in a timely manifesto - *Better doctors, better patients, better decisions: Envisioning health care 2020*[15]*:*

"The 20th century became the century of the doctor, the clinics, and the medical industry."

"The 21st century should become the century of the patient."

Figure 2. Patients are willing to accept higher risks of progressive multifocal leukoencephalopathy (PML) when treated with natalizumab (Tysabri) than physicians. The figure shows the risk at which patients would stop taking the drug, and at which physicians would stop prescribing it (adapted from [8]).



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