

Ethical aspects of risk communication

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Abstract

The essence of risk communication is to provide patients with a clear understanding of the benefits, harms, trade-offs and uncertainties of any proposed treatment. Doctors often assume that they do this well but can overestimate the comprehension of even well-educated patients. We all make complex decisions using intuitive and deliberative thinking and there are hidden sources of bias in decision-making that apply to both doctor and patient. Recent research suggests that patients are best equipped to understand risk when they are simply able to 'get the gist' of the risks involved in their treatment as accurately as possible. This can be achieved by a process of thinking out loud in which the doctor outlines the nature of the problem and the factors they think might be important to the individual patient, while checking carefully for shared understanding along the way. We have an ethical obligation to keep on developing skills in how to convey knowledge with honesty, empathy and respect.

Keywords Cognitive bias; communication skills; health literacy; risk communication; shared decision-making

Introduction

A patient once told me about a specialist whom she had been seeing for many years. This doctor had been sued by a patient for a perceived failure of care and the case had hit the news headlines. Although technically the specialist's care had been impeccable, the experience completely had changed his clinical approach. My patient understood the alteration in his behaviour; she said she would switch off while he reeled off every possible complication of any proposed change in her treatment regimen because she trusted his judgement. The net result of his distressing experience was that his new, overzealous approach was just as inappropriate as no risk communication at all.

The ethical challenges in risk communication

It is not possible to inform every patient of every risk, so we must somehow synthesize and share information about what really matters. Clearly, we have an ethical obligation to keep up to date with the literature in our own specialty and then to translate it into a message that patients can understand. Competence in risk communication includes skill in talking about evidence, skill in providing statistical information in a way that can be understood by a lay person, and familiarity with decision support tools and their application. Excellent courses are readily available¹ and can be found on such sites as

Key points

- Excellence in risk communication is a moral obligation for all physicians
- It is easy to overestimate a patient's ability to understand risk
- It is therefore important to recognize specific limiting factors such as a patient's numeracy and one's own biases in estimating and expressing risk
- The good physician 'digests' and explains complex information with respect and empathy, in order to help patients to identify their priorities and arrive at a decision on treatment

the eLearning for Healthcare platform (<https://www.e-lfh.org.uk/programmes/shared-decision-making/>).¹

How does the doctor described above measure up? He was very good at describing benefits, harms, trade-offs and uncertainties, which are central to risk communication, but something was clearly not right.

Patients' perception of risk

Risk communication is difficult. Think of the challenges posed by the coronavirus disease (COVID-19) epidemic and the number of pitfalls it opened up in both public health and clinical care. Risk communication is particularly challenging when patients have difficulty understanding numbers. As Reyna et al.² note:

Low numeracy is pervasive and constrains informed patient choice, reduces medication compliance, impedes access to treatments, impairs risk communication ... and, based on the scant research conducted on outcomes, appears to adversely affect medical outcomes. (p. 944)

Most patients do not process information about risk scientifically. Everyone is influenced by social, cultural and affective factors as well as age, gender and past experiences of health and illness. To this list we can add their level of interest and confidence in science and scientific thinking, especially in a world where a distrust of science is being actively promoted.

You would probably be disappointed with your patients' responses if you gave them an examination on their understanding of the information you have tried to convey. Gurmankin et al. (see Further reading) studied patients' responses to hypothetical cancer risk scenarios in one of three risk communication formats: verbal only, verbal plus numerical probability as a percentage, and verbal plus numerical probability as a fraction. Regardless of format, patients' risk perception varied widely. Moreover, they tended to overestimate risk, sometimes on the grounds that they thought that the doctor might be trying not to worry them too much!

On the other hand, when the stakes are high, patients and specialists tend to underestimate risk, especially if the treating specialist avoids difficult conversations about the difference between curative and palliative care (see Gawande 2014, in Further reading).

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It is normal to try to reduce uncertainty by searching for simple answers to complex questions. In *Thinking Fast and Slow* (see Further reading), Daniel Kahneman offers a masterful summary of human decision-making that shows how complex decisions are grounded in both intuitive ('system 1') and deliberative ('system 2') thinking. Intuitive thinking is strongly grounded in emotion, and emotions influence perceptions of health risks. An anxious patient may interpret any unusual symptoms as a harbinger of doom, but an overweight, inactive smoker with diabetes mellitus may appear to be relatively unmoved by encouragement to undertake important lifestyle changes.

A doctor cannot claim to be offering patient-centred care if attempts at shared decision-making offer a one-size-fits-all approach that merely confuses vulnerable patients or frustrates both parties. The best doctors try to tailor the message to the patient in front of them.

Clinician bias

Patients are not the only people subject to anxiety or denial. Doctors too are subject to all the usual biases: availability bias, confirmation bias, base rate neglect and overconfidence. Acknowledging the universal vulnerability to bias introduces us to what is perhaps the highest and hardest ethical responsibility – careful and honest self-reflection.

Achieving understanding

Table 1 contains 10 recommendations from the US National Cancer Institute³ and represents a counsel of perfection. Each point is undoubtedly important for risk communication in cancer, where the stakes are high. However, in day-to-day practice, where the risks are relatively low and/or long term, it would be impossibly time-consuming, and not necessarily helpful, to provide detailed explanations of every risk for every patient.

National Cancer Institute 10 steps to better risk communication

- 1 Use plain language to make written and verbal materials more understandable
- 2 If you are presenting data, use absolute risks
- 3 Present information in pictographs if you are going to include graphs
- 4 Present data using frequencies
- 5 Use an incremental risk format to highlight how treatment changes risks from pre-existing baseline levels
- 6 Be aware that the order in which risks and benefits are presented can affect risk perceptions
- 7 Consider using summary tables that include all the risks and benefits for each treatment option
- 8 Recognize that comparative risk information (e.g. what the average person's risk is) is persuasive and not just informative
- 9 Consider presenting only the information that is most critical to the patients' decision-making, even at the expense of completeness
- 10 Repeatedly draw patients' attention to the time interval over which a risk occurs

Table 1

Sometimes it is important to understand what actually happens when we make decisions. This is where strange ideas like 'fuzzy trace theory' might come to the rescue. While facts can be represented in many ways, we unconsciously rely on 'fuzzy memory traces' (i.e. the gist or bottom line significance of a memory) as much as verbatim memories (i.e. the details). This means that we tend to rely on the *gist* of the story, or the 'bottom line,' when weighing up important medical risks.⁴ This is why bottom-line statements, such as 'the risk is high/low', are more informative than statements framed as probabilities or prevalence rates, even for well-educated patients.

Katrina Armstrong⁵ offers this summary of recent research:

Evidence about the prevalence of low numeracy and cognitive biases argues against using potentially misleading levels of precision, even when such numbers are available. For example, the likelihood of a response to therapy can be expressed as a numerical range with a qualitative estimate rather than a single number. Similarly, life expectancy can be explained as having weeks not months or months not years left. For most diagnostic tests, we should emphasize that the test result shifts the probability of a particular diagnosis up or down rather than providing a definitive answer. Finally, the greatest comfort to a patient can be hearing that, regardless of clinical uncertainty, their physician will be with them no matter what the future brings. (p. 819)

The centrality of humanistic values

Armstrong's last point is particularly important. Sadly, but unsurprisingly, one finds that humanistic elements of patient – clinician communication such as empathy, respect or interpersonal skills are rarely included in research on risk communication. In fact, patients sometimes tell me that specialists refuse to answer questions such as 'What would you do, doctor?' or 'If I were your father, what would you advise?' They may even appear to disapprove. However, these questions simply recognize the asymmetry of medical knowledge and experience, and they demonstrate the patient's trust in the doctor's ability to take the 'gist' and turn it into good advice.

A process of thinking out loud can help patients to discover how the doctor themselves is approaching the problem. In listening to this 'out loud' thinking, the patient also has time to process the information. One could say, 'If I were making the decision for myself, I would consider *a* and *b* as important factors, but in your case, *c* and *d* might be more important. I would also want to take account of *x*, *y*, and *z*. On balance, I would probably ... but you might prefer to ...' Assuming you have worked hard to reduce sources of bias in your own thinking, you and the patient can then engage in genuine comparisons and shared decision-making.

Another potentially comforting thought is the fact that your communication with referring general practitioners (GPs) can be used to reinforce risk communication. In complex cases, it is difficult to communicate risk in a single consultation (or in consultations separated by weeks or months), but if you focus on writing a succinct letter that describes the issues clearly, you not only assist the patient and the GP at follow-up, but also have a

clear record of your own thinking about the case at hand. And of course, in the very rare case of a medico-legal complication, excellent record keeping and communication are your greatest allies.

Risk communication is a highly skilled activity that requires personal insight (to avoid bias), conscientiousness (to keep abreast of the latest information in your specialty), honesty (to avoid 'sugar-coating' or judgemental moralizing about lifestyle changes), communication skills (to listen carefully and get the main message across efficiently and effectively) and humanistic values (to do all of this with empathy and respect.) It is critically important for informed decision-making and for genuine care. ♦

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FURTHER READING

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TEST YOURSELF

To test your knowledge based on the article you have just read, please complete the questions below. The answers can be found at the end of the issue or online [here](#).

Question 1

A 48-year-old man, resident in the UK, had had motor neurone disease for the previous 3 years. His prognosis was around 6–9 months. He said that he was terrified of the increasing breathlessness and difficulty in speaking. He asked the doctor about options to hasten his death. The doctor was personally opposed to voluntary assisted dying.

What is the most appropriate response?

- Explain that doctors can never do anything to hasten a patient's death
- Change the subject
- Reassure him about the effectiveness of palliative care
- Explain the situation under UK law
- Warn his relatives about potential for suicide

Question 2

A 39-year-old single mother of four, had triple negative breast cancer with lymph node involvement.

Which element of the information-giving process is most important?

- Information, once provided, should not be repeated because of the risk of confusing the patient
- The relatives must be kept informed
- The prognosis should be discussed early
- Information should be comprehensive and detailed in order to make rational choices
- Information-giving can be augmented by decision support tools

Question 3

A 67-year-old man was reluctant to have a vaccination against Covid-19 because of certain information that he had gleaned from the media.

Which of the following statements that he made is correct?

- There is actually no excess mortality compared with previous years or months
- People are not dying from, but with, COVID-19
- Deaths are mostly from other causes and other underlying conditions
- The number of deaths from COVID-19 has been under-reported
- This is no different from a normal "flu season".