

Risk communication in the clinical consultation

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ABSTRACT – Modern healthcare and modern societies are facing up to the need for greater engagement of patients in treatment decisions. Shared and informed decision-making is replacing traditional paternalistic approaches to decisions; health policy both reflects and drives these changes. A critical contribution to better informed decisions by patients is the effective communication of risk in the clinical consultation. This is not straightforward, but there is a growing evidence base to improve performance in this area to the benefit of both patients and clinicians. The purpose of this review is to provide an accessible and practical guide to better communication of risk by clinicians.

KEY WORDS: communication skills, decision-making, risk communication, uncertainty

Risk communication is the open two-way exchange of information and opinion about risk, leading in the context of healthcare to better understanding and more informed decisions about clinical management.¹ However, this straightforward definition belies the difficulty of doing this effectively.²

There are many reasons why discussing risk with patients in the clinical consultation is increasingly important. The policy agenda in healthcare in the NHS is rapidly changing. There is a major emphasis on choice;³ together with that comes the need to give information that helps patients make more informed decisions. Hitherto, choice has been rather narrowly restricted to issues such as where to be treated. Arguably, choice is more important in making decisions on treatment options where there may be more than one treatment to consider, often with different risk and benefit profiles and long-lasting consequences for the patient.

Thus, there has recently been considerable emphasis on shared and informed decision-making, in contrast to doctor-led paternalistic approaches that have dominated in the past.⁴ In part, this reflects a wider societal change towards a more consumerist society, aligned with increasing expectations of healthcare. However, it also reflects a moral and ethical imperative better to engage patients in decisions that materially affect their health, especially when it is increasingly acknowledged that patients'

values and preferences vary widely and that doctors are poor at predicting these in individual patients.⁵

Furthermore, there is increasing evidence that patients who are better informed and more engaged in decisions about their own care are more likely to be knowledgeable, more likely to adhere to their chosen treatment and may have better outcomes.^{6,7} There has been an explosion of decision aids to help patients participate in decision making and to make informed choices consistent with their values by presenting the clinical evidence and the likely effects of alternative treatments. A key element of such decision aids is the presentation of risks and benefits; it is within this field of endeavour that much of what we now know about good communication of risk arises. Whether or not they use decision aids, though, clinicians have a major task in communicating risks and benefits to their patients.

This article seeks to summarise the present state of knowledge on risk communication in the form of straightforward guidance of practical value to clinicians faced with this difficult task.

Skills needed

Risk communication is not simply an issue of numeracy and presentation; it also requires more generic communication skills.² The 'psychometric' tradition⁸ of understanding risk perception has investigated the fact that some risks tend to evoke more dread than others, regardless of scientific estimates of their likelihood of occurring. When assessing risk, people bring their own beliefs, values and experiences to bear on their decision making.

Key Points

Risk communication is central to effective decision-making in modern healthcare

Risk communication is not straightforward, but there are some simple rules to follow for the clear presentation of risk information

Be honest about what we know

Be honest about what we do not know

Explore people's understanding, reactions and opinions about this information

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This review will not deal with these issues in detail, but it is worth stating that the most powerful preliminary move is for the clinician to display competence, a caring approach and a willingness to discuss the patient's own expectations and fears. This can create an environment for decision making based on trust, which enables people to ask questions and discuss risks fully, providing the greatest opportunity to enhance understanding. It may also be important to remind patients that, as a fact of life, virtually all treatment options are inevitably associated with some possibility of risk.

Language of risk

A range of terms is commonly used in our day-to-day life to describe risk. For example, risk may be categorised as 'low', 'moderate' or 'high', perhaps qualifying these terms further (eg 'very low'). Terms such as 'probable', 'unlikely' and 'rare' may be used; some have suggested the advantages of such vague terms when a numerical expression would imply a level of precision about the risk that cannot be justified by the available evidence.⁹

Interpretation of these terms varies widely from person to person. They are elastic concepts; indeed, the terms may be used variably and inconsistently depending upon the context of the risk being described. This has led to suggestions for a standardisation of terminology such that these terms are applied consistently, for example standardised terms for certain frequencies (eg 'high' for risks greater than one in 100).^{10,11} Others have suggested using everyday examples (eg the risk of dying in a car crash or being struck by lightning) to illustrate the meaning of such terms¹² or analogies to convey levels and nature of risks,¹³ though there is little evidence that patients actually value these approaches.

Such attempts to standardise have some immediate appeal, but most commentators believe that they fail to recognise the dynamic linguistic reality of variable use of terminology and rapid evolution of meanings.¹⁴ Hence, we do not believe this is an appropriate solution to the undoubted problem of the language of risk.

Discussing rates and the reference class

Although there is no single correct way to present risk and probability, it is clear that 'some forms tend to cloud minds, while others foster insight'.^{15,16} For example, the three statements discussed below are not helpful:

'You have a 5% chance of having a stroke in the next year'

This first statement is a single event probability. An individual patient will either have a stroke or not in the next year – it is not possible to have 5% of a stroke. A better way of presenting this information would be to say that 'Of 100 people like you, five will have a stroke in the next year'.¹⁷

'Having mammography reduces your risk of dying from breast cancer by 25%'

The second statement gives a measure of relative risk. However, in the absence of the underlying absolute risk (or event rate) this

can be misleading. Thus, consider the response to the presentation of relative risk data on second-generation oral contraceptives. A media-led panic and considerable anxiety were caused in 1995 when it was announced that they doubled the risk of thromboembolism in women. This doubling of risk represented an absolute increase in risk of 15 episodes per 100,000 'women-years'. This led to anxiety and many women stopped their contraceptive, with subsequent unplanned pregnancies – which in themselves posed a greater risk to the population of women than the pill itself.

A better way to present this information would be to state that 'of 1,000 women who do not have mammography, four will die of breast cancer in the next 10 years, whereas out of 1,000 who do have mammography, three will die.'

'89 in every 100 will get better but one in 25 will have a bleed'

The third statement has the problem that it uses two different denominators in the one sentence. A better way to put this would be to say that '89 in 100 will get better but four in 100 will have a bleed' – using a consistent denominator.²

The common feature of these examples is the use of event rates (natural frequencies) and of a clear reference class (ie to whom or what the risk refers). The general message would be that absolute rather than relative risk should be used, and a common denominator (eg x in 100 compared with y in 100) rather than a common numerator. Avoiding a percentage is preferable since the natural frequency format (30 in 1,000 compared to 4 in 1,000) is much less open to misinterpretation. Consider the psychiatrist who told a patient there was a 20% chance of impotence with Prozac. The psychiatrist meant 20% of the people, but the patient thought he meant 20% of the sexual episodes.¹⁵

It follows that formats such as relative risk reduction, absolute risk reduction and numbers-needed-to-treat can be confusing because they avoid making the baseline risk clear. There is also little appetite for using them among either professionals or patients.¹⁸

Time frames

Presentation of risk not only requires a numerator and a denominator but also needs to present the risk in a given time frame: for example, 'if you consider 100 people like you, three would suffer a heart attack over the next 12 months'. Although lifetime risk is often used, this may not be the most appropriate timescale. A five- or 10-year risk is often better,¹⁹ although our work with older people with atrial fibrillation (AF) found they much preferred a one-year to a five-year risk; this reflected their age and expectations – many did not look forward over a five-year period and realised that in their latter years much could happen over that time.²⁰

Framing

The way that data are presented can make a difference to interpretation.²¹⁻²⁴ Thus, the same outcome can be presented as a

97% chance of survival (positive) or a 3% chance of dying (negative). Positive framing is more effective than negative in persuading people to take risky options, but focusing on only the positives can lead people towards choices they might regret later if they feel the full or balanced picture was not initially provided.²³ Positive framing can also enhance people's understanding of the information presented.²⁵

The obvious solution to the unintended effects of framing is to counter them with dual presentation or in a balanced way, for example by presenting the chances both of survival and of death.²⁶

Conveying uncertainty

It is the nature of the task of conveying risk that we are communicating stochastic uncertainty. Ideally, patients would like to know for certain whether or not they will suffer a heart attack or an adverse drug effect. Such certainty cannot be provided except in very rare instances (eg severe drug allergy, in which case the risk presentation is straightforward!). Hence we need to be able to convey the sense and preferably the degree of uncertainty.²⁷ Unfortunately, using such statistical entities as confidence intervals around event rates is largely unhelpful. The use of phrases such as '100 people like you' and the use of interactive graphical presentations may help (see below), as may such terms as 'our best guess is ...'. We may also need to recognise other uncertainties, such as in our understanding of or ability to predict the significance of a given outcome: for example, carrying the BRCA1 gene for breast cancer where variable penetrance means there is a need to be even more circumspect in the conclusions drawn from 'evidence'.

Visual presentation

Graphical presentation can undoubtedly improve the communication of risk for many people, but graphical presentation needs careful thought and design.²

As with numerical presentation, the various forms of graphical presentation have different implications for the quality of communication. The evidence base is not as extensive as it is for differing forms of numerical presentation, but there is a suggestion that simple bar charts are preferable to more complex representations of data.²⁸ On the other hand, areal presentations (eg pie charts) are less effective.²⁹ None the less, it is useful to provide a range of ways of presenting data to have a better chance of meeting the varying needs of different patients. Furthermore, online or interactive formats hold great promise for us to be able to provide this for patients in the information resources offered to them.

When presenting comparative data it is important that the same scales are used on any graphs or charts to avoid confusion. Visual aids should be pilot tested with the target group to maximise their applicability and interpretation.³⁰

Individualised risk presentation: tailored probabilities

One of the major challenges of clinical practice lies in applying evidence-based information to decisions on individual patients. Studies of the effects of risk communication on a range of outcomes have a greater effect if they concern personalised rather than generalised risk.³¹

Furthermore, it seems self-evident that clinicians should try to present information that reflects as far as possible the impact of the risks and benefits upon the individual patient sitting in front of them. Thus, it is not appropriate to say to a patient with AF that she has a five-fold increase in the risk of stroke, not only because this breaks one of the cardinal rules on using relative risk, but also because this is an average figure for all people with AF regardless of their individual risk factors. In fact, the risk of stroke in patients with AF varies widely depending on individual demographic and clinical characteristics.³²

It is helpful to be able to use, for example, a risk equation that allows a more representative calculation of the risk of stroke for the individual. Several sources of risk assessment for AF are available, including predictive equations derived from the Framingham cohort study and stratified approaches derived from the control arms of randomised controlled trials.^{32,33} Regardless of the individual merits of the different sources for deriving individualised risk, such sources allow the presentation of the risk to be tailored to the individual. For example, a number of facilities exist to enable risk calculation for several clinical conditions such as cancer, heart disease, diabetes, osteoporosis and stroke from the Harvard Center for Cancer Prevention.³⁴

As information on the risks and benefits of treatments and screening becomes more sophisticated, increasingly adept ways of presenting them will be developed. Whilst taking care not to overcomplicate presentations, computer-based calculations can allow for real-time presentation of individual risk and a more interactive means of discussing the risks and benefits of treatment. Being able to enter pertinent clinical details into a simple computer program while the patient is being counselled (Figs 1 and 2) offers several advantages:

- It helps to clarify that risks differ between patients.
- It enhances the personalised nature of the data presented.
- Presenting risks in this way avoids the problem of framing, since it is apparent how many people will have a stroke and how many will not.
- The way the risk is presented can be designed to reflect the probabilistic nature of risk. For example, the smiley face picture in Fig 1 for a 75-year-old man with AF is generated after entering the patient's clinical characteristics (using the Framingham equation) to present the absolute risk of stroke, based upon characteristics which include age, sex, history of hypertension, blood pressure, smoking status and the presence or absence of diabetes, left ventricular hypertrophy and cardiovascular disease. When the calculation is made, the red faces are generated at random, thus graphically presenting the idea that 'of 100 people like you, five will have

a stroke in the next year'. Furthermore, by running the calculation again, the distribution of smiley faces randomly highlighted in the population of 100 faces will change, which helps to explain how the probability of this happening to any one individual is calculated.

When the effectiveness of warfarin treatment is taken into account and the calculations run again to demonstrate the expected reduction in stroke risk, the chance of a gastrointestinal bleed as a side effect of treatment becomes apparent (Fig 2). In addition, in this example the potential effects of smoking cessation and of controlling blood pressure can also be demonstrated. This visual presentation is appealing to many

patients – but not all – hence the data are also presented on the screen as a percentage for those who prefer numerical data.^{20,35}

Remaining challenges

This review has summarised the present understanding of the most effective ways of presenting risk and of those that are ineffective or confusing. Because a particular type of presentation is preferred it does not necessarily mean that the perception of risk is valid. The fact that most people prefer one method does not mean that all will prefer it or that less effective methods are always so – they vary between patients.

There are additional challenges in assessing the effectiveness of risk communication,³⁶ as there are for the wider area of decision aids which usually include some form of risk communication. Should studies measure behavioural or physical outcomes such as pain relief or stroke prevention; should they measure adherence; should they measure cognitive outcomes such as knowledge or accuracy of risk perception (and how can that be assessed); or should they measure affective outcomes such as satisfaction with communication or with the decision made?

Generational differences in computer and internet usage may bring about changes in preference for the delivery of such data, even if not its format; people may prefer to review risk information on their own, either before or after the consultation, to inform their decisions.

Conclusions

Effective risk explanation can enhance knowledge, involvement in decisions about testing or treatment, autonomy and empowerment of patients.¹ Poor communication can cause anxiety, lack of confidence in healthcare professionals and other adverse outcomes. Doctor–patient talk about risk raises issues about lay understanding of conditions, tests and treatments. These aspects need to be explored as well as the numerical or probabilistic ones. Patients react variably to both 'higher' and 'lower' risk status: people with 'negative' test results and low risk assessment may be more anxious about their health status than those deemed to be at higher risk. This reflects feelings that they might be left out of something (ie healthcare) more than a focus on risk itself.^{2,3} Risk information also has potential to weaken an individual's motivation for health behaviour, perhaps because of a feeling of inevitability associated with risk factors or perceived loss of control to change outcomes. Thus, both low and high risk assessments can greatly affect patients' lives. The challenge is to support patients by effectively engaging in counselling, decision making and risk communication.

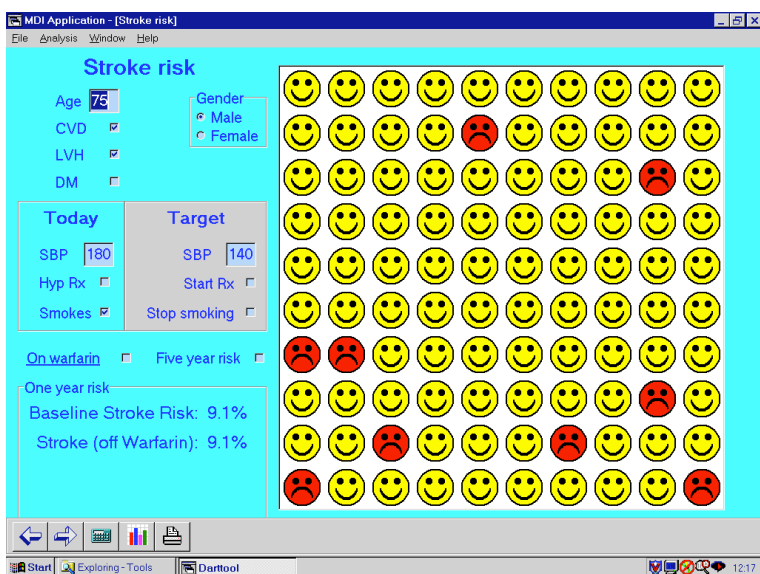


Fig 1. Risk communication for a patient with atrial fibrillation at risk of stroke.

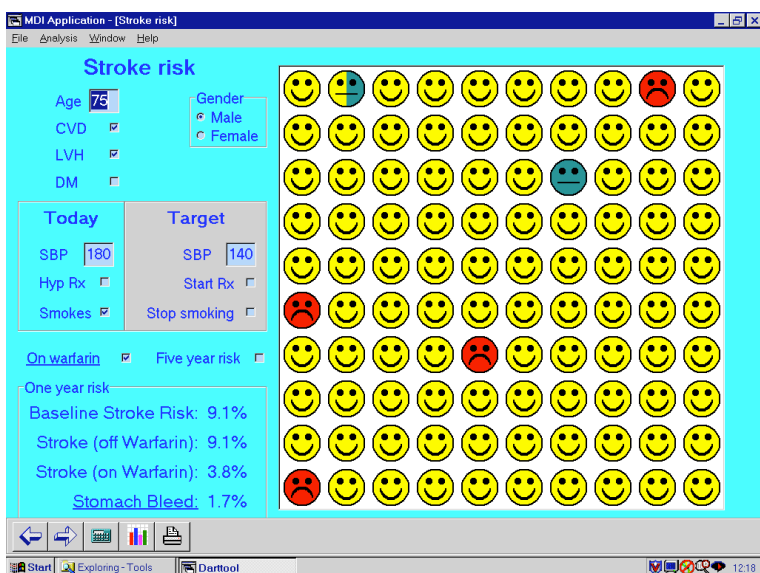


Fig 2. Risk communication for a patient with atrial fibrillation at risk of stroke following treatment with warfarin.

Most areas of clinical medicine have common activities and outputs, including disease management, surveillance for risk of complications and communication issues. We need to address these issues of personal health risk (including predictive testing) and health-related behaviour and risk management, exploring and identifying how people respond to information. A good starting point is to take account of the principles for balanced representation of risk information, as described in this review, and the core requirements of competence and caring approaches to foster trust for these discussions.

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