Communicating risk to patients and the public

INTRODUCTION

Risk communication is an essential part of shared decision making and evidence-based patient choice.[1] Discussing a patient's cardiovascular risk, their risk reduction from taking a statin, the risks and benefits of colorectal screening, or the truth behind the tabloids latest claim that vegetable X reduces the risk of cancer Y by 50%, are all examples of everyday general practice consultations that involve communication about risk information. Effective risk communication is important for the doctor and the patient. Mrs Jones is more likely to choose to take her statin if she understands what is meant by her 10-year cardiovascular risk being 24%, and if she decides based on the information her doctor provides that reducing this risk is worth the trouble of taking a tablet, she may be more likely to adhere to the chosen treatment.[2] Otherwise, it may end up contributing to the large stockpile of pills in her bathroom cabinet. Conversely, both Mrs Jones and her doctor may be satisfied about a decision not to take medication, if it is based on clearly understood information about the harms and benefits of medication.

Risk communication is defined as:

'The open, two-way exchange of information and opinion about risk, leading to a better understanding of the risk in question, and promoting better (clinical) decisions about management.'[3]

The communication of risk has to meet some complex needs for patients, and is difficult to achieve well. Be it a public screening programme or a matter of starting a new treatment, providing evidence-based risk and benefit information to patients and ensuring adequate understanding and accurate perception of such information by patients, forms the cornerstone of informed decision making. Evidence suggests that greater levels of informed choice are associated with greater satisfaction with the process of care and, crucially, improved adherence to the chosen treatment.[2]

Brewer describes three goals for communicating risk. These goals comprise sharing information (the 'just say it' approach), changing beliefs, and changing behaviour.[4] Waldron *et al* highlight the importance of communication strategies that promote belief and behaviour change in their review of effective methods of communicating cardiovascular risk to patients.[5] They stress the futility of directing energy towards the accuracy of cardiovascular risk prediction if the presentation of that risk to patients is not effective enough to promote risk reduction through behaviour change.

This article discusses the challenges faced by clinicians and patients in presenting and digesting risk information, and then using this information to make a health or healthcare decision. An overview of the evidence base behind different methods of risk communication is followed by practical suggestions that attempt to place the evidence in the context of day-to-day practice.

THE CHALLENGE

A number of challenges face the clinician in their task of communicating risk. The first of these challenges lies in the patient's and doctor's levels of numeracy. Numeracy is gaining importance in medical decision making and risk communication.[6] However numeracy is not a universal attribute. Gigerenzer *et al* show how only 25% of the general population could correctly identify 1 in 1000 as being the equivalent of 0.1%.[7] Other studies have found that only 21% of a sample of well-educated adults could answer this question correctly, concluding that even highly-educated participants can have difficulty in understanding simple numeracy questions.[8]

Gigerenzer also describes the concept of 'collective statistical illiteracy' — the lack of basic competencies required to understand health statistics. He describes how this is common to patients, physicians, journalists, and politicians.[7] Patients are presented with an enormous volume of statistical health information. Some of this is misinterpreted by journalists in their haste to create an eye-grabbing headline, or misrepresented by politicians, in an attempt to manipulate or persuade the public. This, along with the patient's own health beliefs, such as 'fear of the disease', a 'trust in technology', and their 'right to access a test', makes the path towards an informed decision much more tortuous. Patients expect their doctor to be able to explain risk in an understandable way that helps them to make an informed decision. Ways of helping patients overcome a fear of numbers and understand statistical concepts are important in overcoming this challenge.

Further challenges for the clinician arise from limitations in the available literature. Despite the large body of evidence, there seems to be a lack of consensus about the most appropriate methods for communicating medical risk.[9] Lipkus states the available evidence has yet to suggest a best practice approach.[10] Reasons for this are the lack of consistency in testing communication formats using the same outcome measure, the relative lack of randomised controlled trials, and the lack of emphasis on developing communication strategies that are built upon a solid theoretical background. Of the studies that are available, very few have used shared decision making or informed decision making as an outcome measure. Most studies look at risk perception, knowledge, or understanding and these may not be the most appropriate measures of effective risk communication.

REVIEW OF THE EVIDENCE

The evidence that forms the basis of this article was identified by searching MEDLINE®, Embase, and PsycINFO®, using the terms 'risk', 'risk communication', and 'informed decision'. Major texts in the field of risk communication were reviewed, including the evidence-based guide to communicating risks and benefits from the US Food and Drug Administration.[11] Well-conducted systematic reviews,[2,12–14] were included as part of the evidence base, as well as authoritative articles about the

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communication of health statistics,[7] and suggested best practice for risk communication.[10,15]

This section provides a brief overview of the evidence behind common strategies that clinicians can use when communicating about risk(s) with patients. Presenting logically equivalent choice situations in different ways is known as 'framing manipulations'.[16] An example of a framing manipulation can be described in the context of prognostic information for a patient with cancer. This can either be 'positively framed' using survival data (for example, 60% of people are alive at 5 years), or 'negatively framed' by using mortality data (for example, 40% of people are dead within 5 years). Framing manipulations have important influences on perceptions of risk and decisions made by patients.[12]

LOSS FRAMING VERSUS GAIN FRAMING
This again refers to how one describes risks and benefits. For example, in the context of screening, one could emphasise the risks and disadvantages of not being screened (loss framing) or the advantage of being screened (gain framing). For a further example regarding smoking cessation, 'You will live longer and healthier if you quit smoking' is a gain-framed message, and 'Smoking causes cancer, heart attacks, and lung disease' is a loss-framed message. In their review, Edwards *et al* found that loss framing messages were generally more effective than gain frames.[12] This effect was small (odds ratio 1.18, 95% confidence interval = 1.01 to 1.38). Newer reviews have reiterated this message but add that loss frames are more effective in situations involving uncertainty and risk, and gain frames work better if the target outcome is a preventative behaviour and the outcome is more certain such as, for example, using car seats to reduce death and injury to children.[17]

NUMERICAL VERSUS VERBAL QUALIFIERS OF RISK
There is an emerging evidence-base about effective ways of communicating probabilities. Patients may have a more accurate perception of risk if probabilistic information is presented as numbers. Numerical values, expressed as event rates in groups with and without the intervention being considered (also called natural frequency formats) should be used where possible. Expressing probabilities as an event rate out of 100, 1000, or 10 000 is better understood by most people compared with a probability format.

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Waldron *et al* systematically reviewed strategies for communicating cardiovascular risk to patients.[5] Of their 15 included studies, four assessed actual risk and the other 11 used hypothetical scenarios. They tentatively conclude that presentation of risk in percentages or frequencies using graphical representations and short timeframes is best for achieving risk reduction through behaviour change. However, better quality trials are needed that compare different risk presentation formats before firm conclusions can be drawn about the most effective way of communicating cardiovascular risk to patients.

Verbal presentation of risk with use of words such as 'likely' and 'rare' appears to be more natural and easier to use than the numerical format, perhaps because people are more skilled in using the rule of language than in using the rules of probability. Furthermore, research shows that people have difficulty in processing the mathematical expressions of probability, and numeracy is low even among highly-educated people.[18]

However, if verbal descriptors are used this must be accompanied by numerical expressions, as verbal descriptors tend to be elastic concepts with a high tendency to be misinterpreted.[19]

PRESENTING MORE VERSUS FEWER DATA POINTS
Zikmund-Fisher and colleagues used the adjuvant online tool (www.adjuvantonline.com) to show the benefit of providing patients with fewer data about breast cancer treatment effectiveness. Instead of presenting patients with the risks of no treatment, chemotherapy alone, hormonal therapy alone, and combined chemotherapy and hormonal therapy, they provided only the two options deemed most appropriate. When fewer options were presented, knowledge and speed of processing increased significantly.[20]

RELATIVE RISK VERSUS ABSOLUTE RISK
Recent studies[21] have shown that the size of the number plays a part in how risk is perceived by the patient. In a study of

acceptance or declining a hypothetical treatment that prevents hip fractures, patients were more likely to accept treatment if benefits were presented in absolute terms, and more likely to decline treatment if harmful effects were expressed in relative terms. Gigerenzer describes communication of the risks of a screening test where identical benefits are described in terms of absolute risk reduction (ARR), relative risk reduction (RRR), or numbers needed to treat (NNT).[7]

- RRR: If you have this test every 2 years, it will reduce your chance of dying from this cancer by around one-third over the next 10 years.
- ARR: If you have this test every 2 years it will reduce your chance of dying from this cancer from around 3 in a 1000 to around 2 in a 1000 over the next 10 years.
- NNT: If around 1000 people have this test every 2 years, 1 person will be saved from dying from this cancer every 10 years.

The results of their study showed that patients were more likely to take this test when it was presented in RRR terms and least likely to take it when presented in NNT terms.[7]

Fagerlin and Peters reiterate these findings and state that NNT is the most difficult format for patients to understand and should not be the sole method of risk presentation. RRR seems larger and causes treatments to be viewed more favourably in studies of the general public and of medical students.[17] And then we have odds ratios (ORs), that are frequently used to present risk information. In their recent article, A'Court and Stevens point out the common misunderstandings in interpreting this; such as assuming ORs to be the same as RRs. They go on to highlight the debate about how this can be exploited by researchers to make their findings appear more dramatic and perhaps publishable.[22]

Another representation format for risk information is the 'prolongation of life' or event postponement; people may be even less inclined to choose to take a treatment if they know that it will prolong their life or postpone a myocardial infarction by a

matter of months, rather than NNT format, or other more persuasive formats such as RRR.[23]

TOOLS FOR COMMUNICATING RISK

Many tools have been used in studies to enhance understanding of risks and benefits and promote informed decision making. Trevena *et al* identified the use of these tools in various risk communication studies.[14] This review concluded that communication tools in most formats (verbal, written, video, provider-delivered, computer-based) will increase patients' understanding but are more likely to do so if they are structured, tailored, and/or interactive. This next section describes some of the tools available to GPs during consultations that may aid effective risk communication.

Tailored information

Tailored health communication refers to providing information to someone based on characteristics that are unique to that person. It is assumed that tailored messages are perceived as more relevant to an individual and are therefore better processed and understood. Tailoring information using an individual's specific risk factors may increase that person's involvement with the information and lead to better understanding.[24]

Online risk calculators in multiple formats can be used to provide patients with individualised (tailored) risk estimates. For example, Mrs Jones who is 56 years of age, smokes 15 cigarettes a day, and suffers from diabetes can have her cardiovascular event risk calculated at 14.3% in the next 10 years, using the Q-risk calculator.[25] The absolute risk is depicted in a 100 face diagram, to aid better understanding. The calculator can also be used to explain to Mrs Jones how her personalised risk is different to the general population of 56-year-olds, expressed as relative risk, which is 2.8 in this case. Furthermore, we could demonstrate to Mrs Jones that smoking cessation would drop her risk down to 10.3% — a 4% drop in absolute risk. Alternatively, if Mrs Jones wanted to discuss

her risk of breast cancer, a personalised risk assessment could be provided using a 'Gail score'.[26]

Consultation summaries or instructions (audiotapes, written, and verbal)

People can find it hard to remember medical consultations. Providing summaries of consultations may help patients remember more of the information, facilitating informed choice. A systematic review[27] of trials using this method in patients with cancer, showed that subjects tended to remember more of the information they were given and some were more satisfied with the information they received.

Decision aids

Patient decision aids are tools that help people become involved in decision making by providing information about the options and outcomes and by clarifying personal values. They are designed to complement, rather than replace, counselling from a health practitioner.[28] Patient decision aids can improve the quality and the process of decision making.[29]

The Patient Decision Aids Research Group at Ottawa Hospital Research Institute maintain an A–Z inventory of patient decision aids, to help patients and clinicians make 'tough' decisions about their healthcare options. 'Tough' (although still ordinary) healthcare decisions may have many options, uncertain outcomes or benefits and harms that people value differently, such as different medical or surgical options for treatment of menorrhagia, or the anti-coagulation options for atrial fibrillation. Declining active treatment (such as in prostate cancer) may also be one of the options that patients wish to weigh up and consider what the best choice is for them personally. There are 324 different decision aids in this inventory, accessible at http://decisionaid.ohri.ca/cochinvent.php. These can be helpful during day-to-day consultations. For example, Mr Jones, a 65-year-old man attends surgery wanting to discuss screening for prostate cancer. Despite the evidence base, this remains a

grey area, with much of the literature advocating a shared decision to be made by patient and doctor. This consultation can be aided by using a web-based decision aid (www.prosdex.com) that displays the relevant risk and benefit information in an understandable manner and guides the patient towards an informed decision.[30]

Evidence-based leaflets

Patients who are provided with supplementary written information in the form of leaflets have a higher level of knowledge when compared with patients who received no written information.[14] Leaflets may aid recall after the consultation and may help Mrs Jones explain to Mr Jones how her risk of a heart attack will be reduced if she stops smoking and why it's important to her to try.

Paling outlines various techniques that can be used to effectively communicate about risk with patients within a 10-minute consultation.[15] These include:

1. Reminding patients that virtually all treatment options are associated with some possibility of risks.
2. Avoid explaining risks in purely descriptive terms (for example, 'low risk') as descriptive terms may convey a totally different order of magnitude to the patient than you intend.
3. By using balanced framing, such as, chances of survival and chances of death.
4. Have a clear reference class — who or what does the risk refer to?
5. Avoid percentages and try to use natural frequency formats, for example, '1 in 5 people', or '12 in 100 people' is much less open to misinterpretation.
6. Use a consistent denominator, for example, 40 out of 1000, 5 out of 1000 instead of 1 in 25 and 1 in 200.
7. Use appropriate visual aids. These can help a range of patients see the risk numbers in context, providing useful information and not just data. Web-based programmes can portray the harms or benefits associated with treatment options with visual aids, such as the Cates Plot.[31]
8. Explore the significance of the risk to the individual, for example, a 'stroke' means different things to different people. This highlights the importance of 'sharing understanding' which may be at least as important as sharing the numerical information.
9. Share uncertainty if it is genuinely unclear

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what the best course of action might be. Honesty may lead to greater professional respect in the long run.

Siegel says: 'The best way to communicate uncertainty of data to patients is to admit that all reports of benefits and risks of therapies are based on estimates of currently available evidence and it is possible that these can change over time'.[32]

CONCLUSIONS

Effective risk communication in modern health care is indispensable. Anyone and everyone involved in healthcare services will increasingly find themselves providing risk information to patients. Gigerenzer tells of a surgeon who said: 'I went into surgery because I knew I didn't want anything to do with psychology or statistics … but now I know I must deal with all of them'.[33] The challenge is to continue trying to improve risk communication in health care, turning data into something more meaningful, relevant, and useful for individual patients. By adopting simple and practical strategies and with the best available evidence base, the prospects now would seem more promising. This field continues to evolve with a significant amount of research underway. Being dynamic and adapting our practice to the new evidence that may emerge out of such research, are the keys to face this challenge.

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