

# Communication about risk — dilemmas for general practitioners

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## SUMMARY

*Measures of risk frequently contribute to our understanding, prevention, or treatment of disease, but it is important that general practitioners (GPs) explain clinical risks effectively to patients to ensure they are not misunderstood, as risk information can assist in decision-making processes and encourage behavioural change. However, the interpretation of risks by patients and doctors varies. It is argued that problems arise because communication about risk is usually framed in terms of the language of chance or probability. In this paper, we describe how probability theory developed, and suggest that attempts to communicate empirical risk processes in probabilistic language are bound to produce dilemmas. We explore how the theory relates to clinical practice and identify key issues that doctors must address in discussing risk with individual patients.*

*Keywords: risk factors; consultations; probability theory.*

## Introduction

GENERAL practitioners must explain risks effectively to patients, or they may ultimately 'run the risk' of being misunderstood. Risk is the possibility of incurring misfortune or loss,<sup>1</sup> and is important in epidemiology, clinical medicine, and everyday life. Measures of risk frequently contribute to our understanding, prevention, or treatment of disease. Modern science and medicine can now achieve more than ever before, but recently public awareness of our inability to explain the risks of treatment or disease adequately with individual patients has grown. This perhaps explains the 'popularity' or public thirst for risk understanding,<sup>2</sup> and the 'epidemic of risk in medical journals'.<sup>3</sup>

Clinical risk communication is not straightforward.<sup>4</sup> The interpretation of risks by patients and doctors varies,<sup>5,6</sup> and the purpose of risk information (to assist decision making or to encourage behaviour change) is not always realized.<sup>7-9</sup> This paper arises from a seminar led by LP that discussed the relationship between probability theory and communication about risks in general

practice. It argues that some of the problems arise because communication about risk is usually framed in terms of the language of chance or probability.<sup>10,11</sup> The seminar explored issues about chance and choice, looking at sociological obstacles to evidence-based health care, principally the problems of translating decisions about groups (the basis of epidemiology) to individual decisions (the core business of clinical practice).

We describe how probability theory developed and suggest that attempts to communicate empirical risk processes in probabilistic language are bound to produce dilemmas. We explore how the theory relates to clinical practice and identify key issues that doctors must address in discussing risk with individual patients. We also identify research opportunities to improve risk communication.

## Historical background: subjectivist interpretation of probability

In the history of probability theory there have been two main interpretations, the subjectivist and the frequentist. The former interpretation arose in the late seventeenth century from the 'games of chance'. It became recognized that the fall of a die or the receipt of a playing card were not haphazard events but were precisely calculable as what are now termed 'a priori independent equiprobable outcomes'. Some events were also observed not to take this equiprobable form, such as the chances of life or death, but attempts were still made to frame variable age-related death rates in the language of equiprobable outcomes.<sup>12</sup>

More importantly, the early probabilists argued that the probability of an event lay not so much in the event itself as in our subjective expectation of it. We may expect to obtain a '6' in six throws of a fair die, but we may be, and frequently are, disappointed in a particular outcome. The same would be true of our 'expectation of life'. In this vein, philosophers argued that we must distinguish between (subjective) probability (based on our expectations and observations of events) and (objective) chance (which exists, but which we may be unable to assess correctly). Thus, although the world is completely determined, our knowledge of it is fragmentary and partial and can only be expressed by inadequate probabilistic judgements. But if we deal in these probabilistic judgements, the question arises how we ensure that such judgements are reliable rather than merely fanciful. The nineteenth century solution to this problem was a simple and stunning strategy, which had a major impact on both mathematics and social science. It rejected the particular and the individual, and focused instead on the collective. This change of emphasis can be illustrated by the problem of predicting the length of a human life.

In the eighteenth century it had been assumed that expectation of life was related to the characteristics of particular and singular human beings. Diderot, for example, argued that it was pointless to consider the chances of a given man dying within the year on the basis of objective evidence (such as the mortality of a group of men of the same age).<sup>13</sup> Rather, we should consider this man, his temperament, his state of health, his 'genre de vie', his profession, and so on.

## Frequentist interpretation of probability

In the nineteenth century, the frequentist interpretation suggested

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we predict the typical length of a human life by studying large numbers of people, taking the sum of the years lived, and then dividing by the number of people studied. Poisson,<sup>14</sup> among others,<sup>15</sup> advocated the study of large numbers as the key to understanding social scientific problems. Large populations showed inherent stability, and the perturbations evident from a study of individual heights, weights, wishes, demands, and behaviour were smoothed out. Thus, the *collective* became the focus for most nineteenth century social science, and chance (i.e. randomness) was recognized to be the property of the collective rather than of singular objects.<sup>16</sup> A further philosophical deduction postulated that the concept of probability only has meaning when referring to the limiting value of a relative frequency in a long series of observations.<sup>17</sup>

#### An example — the probabilities of accidents

Bortkewitsch noted a relative stability in the annual rate of rare events such as child suicides, deaths in different professional groups, and Prussian Cavalrymen killed by horse kicks.<sup>18</sup> In his Law of Small Numbers, he noted also that the number of accidental deaths and suicides fitted the predictions generated by the Poisson distribution.<sup>18</sup> In the United Kingdom's General Household Survey 1987–89,<sup>10</sup> respondents were asked whether they had suffered an accident resulting in injury during the three months prior to interview. The pattern of responses is shown in Table 1.

The data in Table 1 show that the probability of an accident is firmly related to the social context. The probability for a 'person' differs from the probability for a 'male', and from that for a 'single' or 'manual' worker. The same event (one person's accident) can therefore have more than one probability, and one can argue that 'probability of an event' has no exact meaning unless the collective in which this event occurs is precisely defined.<sup>17</sup> The probabilities do not refer to individual occurrences at all, but to the stability of occurrences in a collective. They refer to Quetelet's 'homme moyen' and not to this particular man, woman, or child. The probability of any individual having an accident, cancer, heart attack, or whatever must remain either 0 or 1. All we can assume is that, in the long run,  $x$  proportion of people with  $y$  characteristics are likely to have accidents, cancers, or heart attacks. Whether *this* man, woman, or child will have an accident is forever undetermined. This is what makes the clinician's task in dealing with individual patients so problematic.

Language has been easily laid on top of mathematics so that individuals rather than collectives appear to form the foundation of our risk assessments. The frequentist interpretation of probability, however, cannot even ask what is the probability of *this* man having or doing anything, because a particular event cannot be said to have a long-term frequency. It is only from the subjectivist perspective on probability — from a framework concerning

our degrees of belief — that we can talk about an individual's chance of experiencing misfortune. The Bayesian approach to statistics does integrate the view of probability as a degree of personal belief, which changes as data accrues, with the probability distribution of a population for *public* health decisions.<sup>19,20</sup> In order to make a statement about an individual patient or event, however, a more subjectivist approach is still employed, using other already available information or experience and not data from the collective.<sup>20</sup>

#### Relevance to clinical practice

Does this help us talk about risks with individual patients in everyday general practice? Understanding of risk differs among epidemiologists, clinicians, and lay people,<sup>21</sup> and this derives from the different historical theories of probability.

In epidemiology, risk expresses as a statistical measure the degree of association between a characteristic and a disease within a defined population.<sup>22</sup> Epidemiologists speak of the technical, objective, or scientific features of risk as a measured property of a group of people. This risk is therefore located outside particular individuals. There is a tension, however, between this epidemiological perspective and clinical or lay contexts.<sup>23</sup> Clinicians tend to speak of risk as a specific property of an individual, inferring clinical significance from epidemiological data. In clinical and lay contexts there is a 'language of risk'<sup>21</sup> that synthesizes many meanings, some intended and some subconscious, and that reflects uncertainty about causal relationships and the prediction and control of undesirable outcomes.<sup>21</sup> To the lay person, risk is also a subjective experience (its assessment and evaluation being a social process, not a scientific one); as people may speak of their risk of breast cancer or ischaemic heart disease in the same way that they speak of experiencing other actual symptoms of illness, the meaning of personal risk may be ambiguous.<sup>24</sup>

#### Implications for practice

As the meaning of risk is qualitatively different for lay people and epidemiologists, clinicians find themselves in a dilemma. Should they follow an epidemiological population perspective or an individual approach? Should they adopt the increasingly prominent quantitative, evidence-based population approach when discussing risks in practice, or should they work in the more experiential or qualitative mode that is contextual for the individual?<sup>25</sup> Or can they continue to bridge the two, translating concepts of epidemiological risk into clinical risk for the individual, and attempting to identify with the patient's position and assist their decision making? To make this decision, doctors will need to address a number of important issues concerning their own approach to evidence, risk, and 'risk factors':

- What sort of evidence do I require?
- How should I use the evidence?
- Will detailed information about risks help me in the consultation?
- What advice does my patient actually want?
- How will the patient respond to 'uncertainty'?
- Is the information comprehensible to my patient?
- Is the available information accurate for this individual patient?
- What is my responsibility to patients suffering from being 'at risk'?

First, what sort of evidence do practitioners wish to take into account in assessing and communicating risk, and is it available? The current emphasis on quantitative evidence favours biomed-

**Table 1.** Probability of accidents in a three-month period in a sample of 26 051 people.

Group	Number of accidents observed	Probability of accidents
Whole population	1119	0.0430
Males	646	0.0496
Females	473	0.0362
Unmarried	643	0.0492
Married	476	0.0364
Non-manual	439	0.0336
Manual	680	0.0522

Source: ESRC data files for GHS 1988–89.

ical variables at the expense of personal or contextual variables,<sup>26</sup> but the latter may be a more appropriate contribution to a decision-making process in many situations.<sup>27</sup> Allied to this is the issue of how to use evidence. There can be an obsession with communicating risk information to patients without considering whether it is always to their advantage. The ethical principle of autonomy — maximizing patient choice and responsibility — is assumed to override beneficence. Full explanation of risks, and indeed interventions to manage them, such as prophylactic mastectomy to eliminate the risk of cancer, may be intended to manage (i.e. reduce) our own legal and emotional risks and responsibilities<sup>21</sup> more than those of the individual patient. Practitioners should address the range of different types of evidence they require, and the judicious use of this evidence, and should candidly examine in whose interests the information is being shared.

Having identified the types of evidence required, doctors then need to address what precise information would assist discussion with patients. For example, would data on the incidence of drug side-effects help in advising patients or would this reinforce the dilemmas in applying epidemiological risk to an individual,<sup>28</sup> generating more rather than less uncertainty.

Doctors must identify what information they want, but must also address what information individual patients want. Patients resist changing their behaviour (e.g. they may continue to smoke) even when given information. The Department of Health annotates smoking advertisements with 'Smoking kills', but individual smokers may interpret this and respond 'Yes, but not me'. This suggests in part that the population risk estimates they have been given (in keeping with the frequentist interpretation of probability) are not real enough, or not relevant or important to them as individuals (operating at a more subjectivist level of interpretation). This may also suggest that common information 'exchanges' in general practice are led not by the patient but by the practitioner or agency.

Information requirements may be dependent on context.<sup>29</sup> Some decisions are 'risk versus risk', in which one decides between two risks, such as between two prenatal diagnostic procedures.<sup>30</sup> Other decisions belong to the even more agonizing category of 'risk versus cost', such as choosing between a risky pregnancy and not having children,<sup>30</sup> or making a choice of surgery (lumpectomy or mastectomy) in breast cancer.<sup>31</sup>

These choices depend on accurate assessment of the size of the risk, and also on exploring the consequences and the relative importance attached, all of which may be problematic. There is a growing psychological literature on the impact that general negative attributes of hazards may have on the way individuals perceive and accept risks.<sup>32</sup> These attributes include involuntary exposure to risk, lack of personal control over outcomes, lack of personal experience or difficulty in imagining risk exposure, and benefits not being highly visible or accruing to others.<sup>32,33</sup> There is also evidence of significant individual and group differences in risk perception,<sup>32</sup> and these will all affect the sharing of information when communicating about risks.

When coming to a decision, ignorance is something that patient and doctor share, even if their areas of expertise and experience differ.<sup>28</sup> Doctors must address how they respond to uncertainty, and should recognize that uncertainty is something they can share with their patients, especially as it relates to diagnosis and outcome. If unrecognized, this uncertainty may cause greater patient discomfort than knowing the worst. An open exchange of information may enable the clinician to evaluate the patient's comfort with risk. Some may prefer 'rote' discussion of risks, some may prefer vagueness, and others may simply not wish to know. The 'standard gamble' technique has shown that patients may also be prepared to take more risks (e.g. from drug

side-effects) than their doctors offer them, but one cannot generalize about the degree of risk an individual patient will take.<sup>34</sup> Improved communication skills would enable clinicians to identify how patients respond to discussions of risk and uncertainty, and to give the information they want. Doctors require more training in communicating with patients about medical benefit and risk.

If discussion is to focus on population risk being applied to the individual, doctors need to explore whether the information is being presented in a comprehensible and honest format. The controversy over the side-effects of third generation oral contraceptives showed how risks can be inadequately portrayed. The level of publicity was out of proportion to the absolute risk of venous thromboembolism, and insufficient attention was given to the adverse effects of non-compliance with treatment (something that routinely follows such publicity scares).<sup>35</sup> The risk information was misleading as the risk is not equally distributed, mostly focusing on smokers, and this outweighs the difference in terms of the risk between second and third generation pills.<sup>36</sup> Thus, at the very least, the 'collectives' in which events are considered require more specification if probabilities are to have a more exact meaning. Alternatively, it may be more accurate to recognize that the 'average' or 'mean' patient is rare in clinical practice,<sup>28</sup> and risk communication should take account of this.

Finally, doctors must address the responsibilities that arise from our risk assessment and therefore 'risk generating' activity. Risk leads to changes in personal perceptions of normality, and consequently 'at risk' people fall into a grey zone between health and disease,<sup>21</sup> with substantial morbidity implications. For example, screening programmes for breast and cervical cancer label many healthy women as ill,<sup>37</sup> and women worry awaiting a normal cervical smear result. The psychological burden, therefore, affects the entire screened population.<sup>38</sup> Ironically, searching for personal control over risk often leads to further medicalization,<sup>21</sup> such as undergoing gene testing for breast cancer or Huntington's chorea; while being 'at risk' can mean being treated as definitely having the disease, leading to disadvantage and discrimination.<sup>39</sup> If risk is something from which a patient can suffer, it can and should be clinically treated.<sup>24</sup>

Doctors have a responsibility for patients labelled as 'at risk', and must address their needs more appropriately. Different methods of communicating risk have different psychological effects on patients,<sup>40</sup> and improved communication must be evaluated,<sup>41</sup> addressing not just biomedical health outcomes but a full range of benefits and costs for new approaches. Improvements could address communication about the size of risks and should include adequate counselling,<sup>31</sup> exploring people's responses to the implications of test results, drug side-effects, or surgery. Prospectively, we should perhaps be more careful to portray risk as the property of the population rather than the individual.

## Research

These real issues for practitioners also identify areas requiring research. In particular, we need to know more about how doctors themselves understand and interpret the epidemiological concept of risk, and about the communication requirements and expectations of patients. The epidemiological concept may require broader definition than is currently intended (by epidemiologists) for clinicians who wish to translate them into practice. We need to understand more fully the different interpretation of probability expressions by physicians and patients,<sup>5,42</sup> and the different effects of, for example, presenting absolute or relative risks on decision outcomes.<sup>43</sup>

## Conclusion

Language is easily laid on top of mathematics to make it look as if individuals rather than collectives form the foundation for our risk assessments, but the limitations of epidemiological risk estimates to the individual should be more widely recognized. Applying these risk estimates to individuals is not supported theoretically and ignores the 'language of risk' that characterizes the lay context and meanings attributed to risk.

Recognizing the limitations, however, is only the first step towards identifying what doctors should be doing in their communication of risk and management of individual patients. Doctors have a clinical dilemma to address: should they choose between the population and the individual approach, or can they continue to attempt to bridge the gap between the two? We require a consensus about which approach to favour, what constitutes relevant evidence, and how it should be used and communicated in particular settings. If practitioners do try to bridge the gap between the population and the individual, they must address whether this is honest, whether current risk information is comprehensible to patients, and whether more efforts can be made to identify their information needs appropriately.

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