Cancer: science and society and the communication of risk

Kenneth C Calman

> For many people the only satisfactory way of speaking about the world is in terms of a series of sharply defined categories, the properties of which are exactly known. Such a procedure has great advantages, but it severely limits our powers of speaking about all the variety that we observe around us.
>
> J Z YOUNG, *Doubt and Certainty in Science*

This article is based on the Calum Muir lecture, delivered in Edinburgh in September 1996.

Of all the diseases in the Western world cancer is perhaps the most alarming. Despite a remarkable number of advances in the understanding of the disease and in the treatment of specific types of cancer, it remains an enigma, with much still to be learned. Cancers are of interest not only to the scientific and medical community but also to the public and politicians. Rarely a day goes past without some new breakthrough in cancer treatment or in the identification of another substance or environmental factor which might cause cancer. My title was therefore chosen to emphasise the importance of the role of science in the understanding of disease and its relation to society.

One of the key issues surrounding cancer is the assessment of risk, both from environmental factors and from clinical treatment, and how that risk is communicated to the public. The need for adequate data is therefore clear and is the foundation for appropriate clinical and public health practice. In this regard cancer can be used as a model for a variety of other diseases; because our data are generally better for cancer than for many other diseases it provides examples of how some of the principles involved in the control of a disease can be put into practice.

J E STEVENSON/ROBERT HARDING

Lightning: the risk is negligible

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Summary points

- Epidemiological techniques, and the data generated from cancer registration, are powerful in identifying correlations between diseases and clinical outcomes. They do, however, have limitations in setting public policy
- In understanding issues surrounding risk assessment, perception is a key aspect of understanding patient and public choice. Information sharing is critical
- A proposal for clarifying the language of risk has been put forward for discussion and debate

In this paper I have three broad objectives: to outline the role of cancer registration in the assessment of risks and benefits; to discuss the importance of perception, choice, and behaviour based on the assessment of risk; and to review methods of risk communication and the language of risk.

Assumptions

I begin with two assumptions: firstly, that cancer registration has value and, secondly, that the public has a right to information and to be involved in the choice of treatment. In relation to the first of these assumptions, the value of cancer registration, the ability to assess and plan for population needs, carry out epidemiological studies, and perform risk assessment are clearly of benefit. Cancer registration is also valuable in assessing the outcome of treatment options and identifying the basic research needed into the pathogenesis of individual cancers. Linked to geographical information systems, cancer registration can provide a remarkable range of information at a series of different population levels.

Nevertheless, cancer registration is not without its problems. Incomplete data and inadequate data are perhaps the greatest. When particular cancers have a low incidence it is often difficult to make links between particular factors and the cancers themselves. While correlations may be identified, establishing a plausible hypothesis and testing it are often much more difficult.

It is also a fair assumption that the public should be involved in the understanding of why cancers are caused and be encouraged to avoid risks of developing cancer. When a variety of treatments are available the use of registration data in identifying best practice can also inform individual patients and allow them to have a choice over the method of treatment which suits them best.

Here too there are problems. The most important is perhaps the uncertainty arising from lack of data and the difficulties of making a full risk assessment. While individuals may be able to avoid some risk factors, they may not be able to avoid others, which may seem to be imposed on them. Thus simply identifying a risk factor may not be enough.

The role of cancer registration in the assessment of risks and benefits

Many examples exist of the identification by epidemiological techniques of factors associated with a higher incidence of cancer. The most obvious are ciga-

rette smoking and lung cancer, radiation and skin cancer, cervical cancer and high risk behaviour, the genetic implications of cancer, Burkitt's lymphoma, associations with radon and dioxins, and a whole range of occupational cancers. These make it clear that under some circumstances the risks can be identified and measured and, where appropriate, avoided or removed.

Cancer registration also allows better identification of treatment options. Best practice can be identified by the use of randomised controlled trials. Staging and prognostic factors can also be identified and allow better stratification and more accurate assessment of outcomes. Of particular interest is the relation between the specialist treatment centre and the generalist treatment centre. This is an important current debate.[1] Lastly, there is the issue of the publication of outcomes for the benefit of the public and of individual patients. These are clearly important issues and relate directly to the quality of the evidence available.

This leads to the next major issue: the problem of certainty in science. For each of the factors mentioned there are limits to the confidence of the data. In some cases when asked, "How sure are you of the data?" the epidemiologist has to hedge the outcomes with a variety of caveats. This significantly weakens the case and can make it difficult to set public policy.

The problem for decision makers arises not when the evidence is clear but when it is weak or incomplete, or even at the stage of a hypothesis. In this instance decision makers generally have two options. One is to go beyond the evidence and act in a precautionary manner and the second is to wait until the evidence becomes clear. This may take years or even decades. In some instances there may be a third option, that of prospectively dealing with the risk factor. In this process there needs to be a judgment about the quality of the evidence and implications of acting on that evidence. This requires openness and sharing of information.

Some examples can highlight this. For example, several studies have related diet to the development, or prevention, of specific cancers. On occasion evidence seems persuasively consistent, at least at first sight. For example, low dietary intakes and plasma levels of β carotene have been associated in both case-control and prospective studies with an increased risk of lung cancer.[2-4] However, subsequent data have failed to confirm this association as causal. Close examination of the data shows that in many cases this link is not quite as clear and obvious as it might seem. Another example would be the possibility of non-ionising radiation causing some forms of cancer. The data in this area are weak, but a link has been suggested in some studies. A plausible hypothesis linking non-ionising radiation and cancer has not been developed. A third example is the use of small area statistics in identifying a link between a point source of an environmental hazard and the development of a specific cancer. Even though the technology has advanced considerably, several important uncertainties remain. Finally, the treatment of breast cancer can be considered as a example of uncertainty. This is one of the most intensively studied diseases across the developing world, but uncertainty continues about best management, what to advise patients, and what to include in any national guidelines.

This leads to one of the major issues affecting those who make decisions about public health: the relation between the science base, the knowledge available, the evidence accumulated, and the public policy which derives from them. This can be extraordinarily difficult, and the costs of taking action based on minimal evidence or simply on the basis of a proposed hypothesis can be very considerable indeed. Thus, although epidemiological techniques, and the data generated from cancer registration, are very powerful in identifying correlations between diseases and clinical outcomes, they do have limitations in setting public policy.

The importance of perception, choice, and behaviour

The discussion so far has been based on the assumption that identifying a risk factor which involves an individual changing his or her behaviour is straightforward and clear. This is generally not the case, however. How people perceive health issues and risk and how they make choices about their own behaviour do not always fall into a rational pattern.

Before discussing this further a few definitions may be helpful. Firstly, a hazard is a set of circumstances which may have harmful consequences. The probability of a hazard causing such effects is the risk of the adverse event occurring. A hazard is therefore a potential risk but does not indicate whether the adverse event will occur to a particular individual, even though we can be sure that adverse events will affect some individuals. Infections, environmental hazards, procedures, treatments, and investigations all carry both risks and benefits. It is how the individual perceives these risks and benefits which is perhaps the most important issue.

Take the problem of cigarette smoking. The risk is clearly established, yet 30% of adults continue to smoke in spite of knowing what these risks are. In this instance the value of smoking must be seen to the individual to be greater than the value of stopping smoking. Over the past few years a wide variety of "health scares" have shown that the public can very rapidly change its behaviour, based on evidence which is often quite weak. Perception remains important, and in the words of Kant "We see things not as they are, but as we are." Although the risk of a hazard occurring may be small, individuals may choose not to take even such a small risk and therefore avoid it.

An important distinction needs to be made between absolute and relative risk. This is best exemplified in relation to oral contraceptives and the risk of venous thrombosis by combined oral contraceptives. Certainly the relative risk of venous thrombosis (defined as venous thrombotic episodes) is doubled with the new pills compared with second generation ones. However, the absolute risk is minimal for both types of pills and is much smaller than the risk of pregnancy. The public presentation of these figures caused great anxiety, yet the increase of risk is very small indeed (table 1). The message to continue to take the pill seemed to be ignored in the pressure for action.

Table 1—*Risks associated with the use of oral contraceptives*

	Venous thrombotic episodes per 100 000 women/year	Mortality per 1 million women/year
No use	5	0.5
Pill	15	1.5
Low dose pill	30	3.0
Pregnancy	60	6.0

The possibility of unknown or unpredicted side effects is a cause of further concern. These may happen many years after the treatment or exposure and may affect all or only a small proportion of those treated or exposed. This is the nature of the development of new treatments or investigations. Their immediate benefit of the treatment may be great—or indeed may be demanded by the public—who only later realises that the long term consequences may be associated with adverse events. Science is expected to deliver. But the public needs to understand more about the nature of

Table 2—*Descriptions of risk in relation to the risk of an individual dying (D) in any one year or developing an adverse response (A)*

Term used	Risk range	Example	Risk estimate
High	≥1:100	(A) Transmission to susceptible household contacts of measles and chickenpox[6]	1:1-1:2
		(A) Transmission of HIV from mother to child (Europe)[7]	1:6
		(A) Gastrointestinal effects of antibiotics[8]	1:10-1:20
Moderate	1:100-1:1000	(D) Smoking 10 cigarettes a day[9]	1:200
		(D) All natural causes, age 40[9]	1:850
Low	1:1000-1:10 000	(D) All kinds of violence and poisoning[9]	1:3300
		(D) Influenza[10]	1:5000
		(D) Accident on road[9]	1:8000
Very low	1:10 000-1:100 000	(D) Leukaemia[9]	1:12 000
		(D) Playing soccer[9]	1:25 000
		(D) Accident at home[9]	1:26 000
		(D) Accident at work[9]	1:43 000
		(D) Homicide[9]	1:100 000
Minimal	1:100 000-1:1 000 000	(D) Accident on railway[9]	1:500 000
		(A) Vaccination associated polio[10]	1:1 000 000
Negligible	≤1:1 000 000	(D) Hit by lightning[9]	1:10 000 000
		(D) Release of radiation by nuclear power station[9]	1:10 000 000

science, and the real differences of opinion which may occur during the often unstructured process of discovery.

In clinical terms the risk benefit analysis is similar. For example, a patient may have a 1 in 100 chance of benefiting from a particular form of treatment, and he or she may opt to take that chance. However, another 99 patients may have ineffective treatment, and treatment which may lead to serious side effects. Thus in understanding issues surrounding risk assessment, perception is a key aspect of understanding patient and public choice. Information sharing is critical.

The language of risk

How then can risks be described and what does the language mean? Risks are described in a variety of ways, such as negligible, minimal, remote, very small, small etc. The public and professionals are rightly confused by such a range of words. A classification is required to help in the understanding of the process; as well as the size of the risk the classification needs to include concepts such as avoidability, justifiability, and seriousness.[5]

Avoidable-unavoidable—Whether a risk is avoidable or unavoidable is an important distinction and can radically shift the perception of risk. If it is avoidable this allows the individual to exercise choice and for the public to be involved in decision making.

Justifiable-unjustifiable—These words carry values with them, and risks may be taken in some instances but not others. For example, the use of a drug, with its known side effects, may be justifiable to treat a particular condition. If, however, the drug also carried a risk of damaging an unborn fetus its use in pregnancy for the same condition might not be considered justifiable.

Acceptable-unacceptable are value laden words but need to be used in a particular context. In general an unacceptable risk would not be tolerated except for special reasons in special circumstances. For example, the use of an unproved method of treatment may be acceptable as a therapy of last resort.

Serious-non-serious again are words which refer to particular situations but in this instance refer to risks which are life threatening or likely to cause disability or severe morbidity. In the case of clinical conditions they need to be put in the context of the diagnosis, which may be minor or life threatening.

Central to these provisos is a risk-benefit analysis and how this is perceived by individuals. Some may not wish to take any risks in spite of the possibility of real benefit. Others will take a chance even when the benefit is likely to be low. With these provisos the following classification might be used. It draws on a great deal of other work and is an attempt to answer the public's questions as to what is meant by safe. This classification is relevant only in relation to the description of risk and not in relation to how that risk might be managed. It is put forward for debate and is not meant to be a final classification.

Negligible—This would describe an adverse event occurring in less than 1 per million episodes or treatments. Such a risk would be of little concern for ordinary living if the issue was an environmental one or for the consequence of a health care intervention. This does not mean that the event is not important—it almost certainly will be to the individual—or that it is not possible to reduce the risk even further. Other words which can be used in this context are "remote" or "insignificant." If the word "safe" is to be used it must be seen to mean negligible but should not imply no risk at all.

Minimal—This would mean that the risk is in the range of 1 in a million to 1 in 100 000 and that the conduct of normal life is not generally affected as long as reasonable precautions are taken. The possibility of a risk is thus clearly noted. In public policy terms it might be described as "acceptable," though for individual decisions a risk that is acceptable to one person might not be to another."

Very low—This would describe a risk of between 1 in 100 000 and 1 in 10 000; many healthcare interventions have adverse effects that are this frequent.

Low—This would relate to a risk of between 1 in 10 000 and 1 in 1000. Once again many risks of clinical procedures and environmental hazards fit into this broad category. Other words which might be used include "reasonable," "tolerable," and "small."

Moderate—This would relate to a risk of between 1 in 1000 and 1 in 100. It would cover a wide range of procedures and treatments and environmental events.

High—These become fairly regular events and would occur at a rate greater than 1 in 100. They might also be described as "frequent," "significant," or "serious." This category might be further subdivided into two: from 1 in 100 to 1 in 10, and greater than 1 in 10.

Unknown risk—This circumstance occurs when the level of risk is unknown or unquantifiable. This is not uncommon in the early stages of an environmental event or the beginning of a newly recognised disease process. The beginning of the HIV epidemic would be an example of this.

The risk of death from playing soccer is very low (this player survived)

The use of these terms is further described in table 2, which uses these terms to describe a range of different risks, some familiar, some less so. Where precisely a risk falls within this classification is often a matter of debate. Risks may vary from time to time, with changing circumstances and information on the level of risk. It is possible, for example, for new research and knowledge to change the level of risk.

COMMUNICATING RISK

The foregoing discussion leads naturally to a consideration of how best to communicate the level of risk associated with a particular health or healthcare issue to the public.[11 12] The media have an important responsibility here. A number of guidelines have been described and they include: the importance of credible sources of advice, openness, sharing uncertainty, the need to accept the public as partners, careful planning, listening to concerns, coordinating with other credible sources, and the importance of meeting the needs of the media.

This preliminary classification of the terminology relating to risk should be the subject of further debate. However, it does emphasise the importance of ensuring that the public are full partners in the process of risk assessment and management, and it is only with such involvement that progress can be made.

The synthesis

This paper brings together three streams of thought: firstly, the need for appropriate evidence in making decisions; secondly, the importance of human behaviour and making choices; and, thirdly, the development from this of public policy. Clearly while the science base and the knowledge base are important, unanswered questions remain and there is often real uncertainty in science itself. This makes it difficult to present the public with clear information in all cases. The public should have a right to as much information as is available, but people also have to recognise that this information may not be complete and that it may not be possible to provide further information on a particular issue without more work, resources, and, in particular, time. Nevertheless, individuals need to make choices, and the individual perception of risk is important.

From a public policy point of view, therefore, whenever possible a risk assessment should be evidence based. When there is uncertainty, however, the decision on the need to take precautionary action or to wait and see is an extremely difficult matter and requires judgment and the participation of the public.

In summary, if the maximum benefit is to be gained from the collection and the analysis of data the public must be seen as full partners in the process, but the public must also recognise that the uncertainty of science remains a significant issue. Cancer provides a good model to consider such issues and from which to derive general principles.

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Distinguishing acute disseminated encephalomyelitis from multiple sclerosis

Genetic predisposition may differ

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An acute inflammatory disease of the central nervous system may be associated with an infectious illness, and when this is an isolated event it is termed acute disseminated encephalomyelitis.[1 2] The inflammation and oedema may be succeeded by demyelination, and similar features may be precipitated by infection in patients with a predisposition to multiple sclerosis. We present the case of a patient with an acute demyelinating condition and discuss the distinction between acute disseminated encephalomyelitis and multiple sclerosis.

Case history

A 33 year old woman presented with rapidly progressive loss of vision in her left eye. Four weeks previously she had had a non-productive cough and had received a five day course of antibiotics. The next week she had gone on holiday to Crete, where she developed a vomiting illness that persisted. A few days later she had noticed loss of sensation in the perianal and perineal region, with hesitancy and loss of sensation on micturition, and constipation. This had been followed a couple of days later by a numbness and paraesthesia, which progressed down both legs, with a similar sensation in the left hand. Nine days before presentation she was aware of a scotoma in her vision from the left eye, which progressed over the next five days to loss of vision with no appreciation of light in that eye, accompanied by pain on eye movement. She then noticed a loss of sensation in the right hand and tingling sensation around the left ear and neck, with slight slurring of speech. She had no history of any neurological symptoms or other illness and no family history of neurological disease.

EXAMINATION

She was generally well and without fever, with no abnormalities on cardiovascular, respiratory, and abdominal examination. She had a wide based, slightly spastic gait. There was slight increase in tone in the legs, with a mild pyramidal weakness in the right arm and leg. She had slight incoordination of the left arm. Pin prick sensation was impaired to both knees, with additional loss of sensation perianally and in the perineal region. There was a milder alteration of sensation, with sensory level at the fourth thoracic segment. Proprioception was absent in the right toe but present at the right ankle, with instability on Romberg's testing.