Just what the doctor ordered? Issues in risk communication in the health domain

Katrina Attwood

Outline

- The challenge
  - Costs (human and economic) of preventable health problems
  - Cultural issues
- Issues with communicating percentage-based information
- Risk communication and trust – case study: UK Government's handling of BSE/CJD
- Implications for HISE

Why do we need to worry?

- 2,148,000 deaths in USA in 1990
- Of these, 40% plus due to 'modifiable factors'
  - Smoking, diet, sedentary lifestyle, alcohol, sexual risk behaviour, illicit drug use
- A further 10% due to 'modifiable causes'
  - Occupational hazards, environmental pollutants, food contaminants, preventable disease

Source: McGinnis and Foege (1993)

Cost of health-related behaviour

Table 3 Percentage of total National Health Service costs attributable to different diseases in 1992–3 and 2001–2

Cause	% of NHS Total costs 1992–3 (£ millions)	Costs 2002 (£ millions)	PAF for DALYs lost within specific disease to physical inactivity*	Cost owing to physical inactivity (£ millions)
Infectious diseases	1.0	702		
Cancer (malignant and other neoplasms)	4.1	2878		
Cardiovascular diseases	12.1	8494		
Diseases related to physical inactivity				
Ischaemic heart disease	3.3	2287	23	526
Cerebrovascular disease	4.1	2892	12	347
Breast cancer	0.3	240	11	26
Colon/rectum cancer	0.5	383	16	61
Diabetes mellitus	1.0	675	15	101
Total	9.2	6477		1062
Musculoskeletal diseases	7.8	5476		
Mental and nervous system disorders	25.0	17 550		
Respiratory diseases	6.2	4352		
Injuries	3.8	2668		
Other	40.0	28 080		
Total	100.0	70 200		

DALY, Disability Adjusted Life Years; NHS, National Health Service; PAF, population attributable fraction.
Note: Diseases related to physical inactivity are a subset of the cardiovascular disease group.
*Attributable DALYs lost within disease due to physical inactivity as a percentage of total DALYs lost to disease.

Source: Allender et al (2007)

Costs (continued)

- Indirect Costs increase the ill-health burden of lack of physical activity:
  - Days lost to sickness absence and premature mortality, private healthcare costs, home care costs
  - Leal et al (2006) calculated indirect *healthcare* costs of cardiovascular disease in UK in 2003 = £21 billion
  - UK Department of Health (2005) estimates indirect cost of lack of physical activity as £8.2 billion annually
    - *Excluding* contribution of physical inactivity to overweight and obesity, which cost a further £6.6 - £7.4 billion annually

Source: Allender et al (2007)

What the Doctor Ordered

- Until recently, dominant tradition in doctor-patient communications was 'paternalism'
  - Doctors made the decisions and carried out all the treatment
  - Treatment decisions rarely justified to the patient
  - No patient involvement in decision-making

It is a poignant footnote to the founding of the NHS that Nye Bevan should have died of cancer without ever having been told of his diagnosis (Calman et al, 1999)*

**Aneurin 'Nye' Bevan (1897-1960), Deputy Leader of the Labour Party, spearheaded founding of the NHS in 1948*

Shifting the Balance

- NHS *Patient's Charter* (DoH, 1992): a patient has the right *"to be given a clear explanation of any treatment proposed, including any risks and any alternatives, before [he] decides whether [he] will agree to the treatment"*
- UK National Plan for the NHS (DoH, 2000) introduces 'informed consent' …

Informed Consent

- Clear guidance about the information patients must be given before making decision:
  - Diagnosis
  - Likely prognosis if left untreated (incl. uncertainty)
  - Options for further investigation
  - Options for treatment /management, including the option not to treat
    - Information about the probability of success/failure of the different options, and about different lifestyle changes which might be entailed

- NB: This is more than just information provision: people need to be enabled to understand the information that they are given and to apply it to their own circumstances

Patient's Role in Medicine

- Patients are Stakeholders in decision-making
  - Sometimes, too much so for comfort, perhaps…
- Requirements to change behaviour
- Requirements to self-medicate
  - Compliance is an issue
    - 50% of people don't finish a course of antibiotics
    - Shouldn't think there are many who don't take all their chemo drugs!
    - Issues with correct dosage, timing, with/without food etc
  - Responsibility to yourself e.g. not to underestimate side-effects

Changing responses to risk communication

- Literature has moved
  - From an emphasis on public misperceptions, with a tendency to treat all deviations from expert opinion as products of ignorance or stupidity
  - Via empirical investigation of what concerns people and why
  - To approaches which stress that public reactions often have a rationality of their own

Source: Bennett (2000)

Definitions

- Usual definition of 'risk' in UK medical domain from Royal Society Study Group (1983):
  - "Probability that a particular adverse event occurs during a stated period of time, or results from a particular challenge. As a probability in the sense of statistical theory, risk obeys all the formal laws of combining probabilities."

Risk Assessment versus Risk Perception (1)

- Risk assessment: quantification of risk
  - Subjectivity comes into play here too (Redmill, 2001)
  - Issues in getting accurate measures, esp. when risks are very small
  - People modify both their levels of vigilance and their exposure to danger in response to subjective perceptions of risk
  - Reporting rates
  - 'Severity iceberg' (Adams, 1995): certainty of data increases as severity of injury increases – fatality stats are reliable, minor injuries least reliable.

Risk Assessment versus Risk Perception (2)

- People are people – most reply on intuitive risk perceptions
  - Based on beliefs, attitudes, judgements, feelings
  - Wider cultural values – behavioural norms and media reporting
  - Personal experience, social networks
- 'Psychometric paradigm' to explore this: perceived risk is quantifiable and predictable, but is still inherently subjective (Starr, 1969):
  - Public will accept risks from voluntary activities (e.g. skiing) that are approximately 1000 times greater than they would from involuntary hazards providing the same level of benefit.

Fright Factors

- Attributes of a risk most likely to invoke anxiety (Bennett, 1998):
  - Involuntary, rather than voluntary
  - Threatens a form of death, illness or disease which arouses a particular dread
  - Damages identifiable victims
  - Poorly understood by science
  - Subject to contradictory statements from responsible sources or the same source
  - Inescapable
  - Arises from unfamiliar or novel source
  - Results from man-made rather than natural causes
  - Causes hidden and irreversible damage
  - Poses particular danger to children, pregnant women or future generations
  - Inequitably distributed

Representativeness Heuristic

- Comes into play where people are asked to judge probability of an event's belonging to a particular class
  - Tversky and Kahneman (1974): events representative or typical of a class assigned a high probability. An event similar to others in a population considered to be representative
  - Ignores sample size or underlying base rates
  - Misconceptions of chance
    - Assume that essential characteristics of a process will be represented not only in the entire sequence, but also locally in each of its parts (e.g. Gambler's Fallacy)

Availability Heuristic

- Estimating frequencies of events on the basis of how easy or difficult it is to call instances to mind
  - Can be based on frequency – i.e. we tend to recall things that happen most often in the past
  - But judgement often influenced by relative salience of instances:
    - Lichtenstein et al (1978): causes of death which attract more publicity (e.g. murder) likely to be judged more likely to occur than those attracting less publicity (e.g. suicide, certain types of cancer)

- BUT NB: particular source of information adopted will depend on the context and on individual difference factors
  - People with a familial history of disease more likely to rely on content of recall, while those without more likely to rely on ease of recall

Numerosity and Anchoring

- Numerosity: judgements of quantity influenced by the no of items making up the total, e.g. more pizza slices, greater estimated area of circle (Pelham, 1994)

- Anchoring: judgement affected by an 'anchor' given – make adjustments from this starting position when judging probabilities
- (Lichtenstein 2008): people judge number of murders higher if they're given a large example estimate (i.e. 50,000 deaths in motor accidents, as opposed to with 3 in swimming accidents)

Problems with Percentages (1)

Fifty percent of the public doesn't actually know what 50% means

Patricia Hewitt, UK Secretary of State for Trade and Industry,
Independent 30th November 2002

- Gigenrenzer 2002
  - Sample of 1000 Germans
  - **Over a third** unable to answer the following:

What does 40% mean?

- 1 in 4

- 4 out of every 10

- every 40th person

Problems with Percentages (2)

- Percentages often ambiguous:
  - "There is a 40% chance that it will snow tomorrow"
    - Snow 40% of the time?
    - Snow in 40% of given area?
    - Snow on 40% of 'days like tomorrow'?
    - It's quite likely to snow, but more likely not to
- Reference class often unclear when single event probabilities are defined as percentages:
  - Gigenrenzer 2002 psychiatrist telling patients "30% - 50% chance of developing a sexual problem (e.g. impotence) from taking Prozac
  - Patients interpreted as meaning that, if they took the drug, something would go wrong on 30% - 50% of occasions

Percentages as Frequencies

The probability that a woman of age 40 has breast cancer is about 1%. If she has breast cancer, the probability that she tests positive on a screening mammogram is 90%. If she does not have breast cancer, the probability that she nevertheless tests positive is 9%.

What are the chances that a woman who tests positive actually has breast cancer?

Source: Gigenrenzer 2002

Natural Frequencies

Think of 100 women. One has breast cancer, and she will probably test positive on a screening mammogram. Of the 99 who do not have breast cancer, 9 will also test positive. Thus, a total of 10 women will test positive.

How many of those who test positive actually have breast cancer?

Verbal Probability Labels

- Except where odds are objectively measurable, people feel more at ease using verbal probability expressions to *communicate* risk (Renooij and Witteman 1999), but they prefer to *receive* info in numerical form (Wallsten et al 1993
  - Labels convey a level of uncertainty, and imply a degree of imprecision about the extent of the uncertainty
  - 'Natural' form of communication
  - Verbal descriptions of uncertainty allow for associative and intuitive thinking
    - Human behaviour isn't always based on deliberate, rule-based thinking

- Variation in how labels are interpreted, influenced by context, experience of the individual etc
  - Toogood 1980: interpretations of 'often' from 28% to 92%
  - Bryant and Norman 1980: physicians' interpretations of 'likely' varied from 25% to 75%

Role of Context

- Verbal descriptors more sensitive than numerical values to manipulations of context and framing
  - Wallsten et al (1986):
    - lower numerical equivalencies assigned to the same verbal expressions when applied to events that were assumed to happen only rarely
  - Weber and Hilton (1990):
    - probability judgements influenced by the severity of the outcome – lower estimates for more serious outcomes
  - Moxey and Sandford (2000) :
    - Interpretation of natural language quantifiers in part dependent on prior conceptions of what the proportions being described might be. This applied to commonplace risk quantifiers 'negligible', 'small', significant' etc
  - Abramsky and Fletcher 2002: health professionals' and lay people's responses to words commonly used in prenatal diagnosis counselling:
    - 88% of the research sample felt that being told of a RARE chromosonal abnormality was more worrying than being told of a COMMON one

Context and Probability

- Numerical probability not immune to effects of context:
  - Windschitl and Weber (1999) – when people told a woman had 30% chance of developing malaria on holiday, their degree of certainty as to whether she would develop the disease varied according to whether the trip was to India or Hawaii.
  - Windschitl et al (2003) – people's adjudged target group to be vulnerable to a disease when the incidence in the context group was low, rather than high

Different numerical forms (1)

- Halpern et al (1989): patients given statistical evidence about chances of death due to circulatory disease in oral contraceptive users:
  - 99,991.7 out of 100,000 will not die
  - 0.0083 percent probability of dying
  - 1 in 12,000 dies
  - 8.3 in 100,000 die
  - 4.15 times greater risk of death
  - 415 per cent greater risk of death
- Different formats result in very different judgements of probability of death
  - E.g. Participants rated 415% greater risk as much worse than 4.15 times higher risk

Different numerical forms (2)

- Yamagishi (1997): presented people with two different statements about a kind of cancer and asked them which they judged to be more risky
  - Kills 1286 out of 10,000 people
  - Kills 24.14 out of 100 people
- First judged to be more risky, even though the second is twice as high
- People's judgements affected by number of people killed
- People pay insufficient evidence to the size of the sample
- Implications for presenting probability information in '1in X' format

Relative and Absolute Representation

- Giving people information about *relative* risk reduction can have a greater influence on their judgements and behaviour than info about *absolute* risk reduction:
  - HRT increases risk of breast cancer after 5 years by 30%
    - Patients scared by this, and frequently reject HRT
    - If patients are informed that absolute risk increase is 10% - 13%, they're more likely to have the treatment
  - Nexoe et al (2002): doctors and health policy makers more likely to make medication available if information presented in relative terms.

Provide the baseline

- Biasing effects of relative risk reductions reduced by presenting both relative and absolute information (Schechtman 2012)

- And by providing a baseline level of risk (Leung 2002)
  - 1995 pill scare, women should have been told not only that there was twice the risk of thrombosis with the pill, but also that the initial level was 15 cases per 100,000

Cumulative Risk

- People have difficulty in judging cumulative risks, as opposed to single-event frequencies
- Shaklee and Fischoff (1990): adults generally underestimate the rate at which contraceptive failure accumulates through repeated exposure
- Linville et al (1993): asked college students to estimate risks of HIV transmission from a man to a woman as a result of 1, 10 or 100 occurrences of protected sex
  - For 1 contact, mean estimate 0.10 (significant overestimation)
  - For 100 contacts, mean estimate 0.25

Positive Framing

- Halpern et al (1988):
  - 99,991.7 out of 100,000 will not die
  - 0.0083% probability of dying
  - First format led to significantly lower risk estimates
- Positive framing effects
  - Estimates of death rates differ widely when asked how many die, and how many survive (Fischoff 1983)
  - McNeil 1982: (imagined) lung cancer – 44% chose radiation therapy when info framed in terms of cumulative risk of survival; 18% when info framed in terms of risk of death
  - Armstrong 2002: people receiving survival curves significantly more accurate in answering questions about the information than those receiving mortality curves

Negative Framing

- Telling people about risks of not undergoing screening (loss framing) leads to greater uptake of screening than does telling them about benefits of screening
- Findings not consistent
- Seems to be a distinction between detection behaviours and prevention behaviours
  - Loss framing better for detection behaviours, gain framing for prevention behaviours

Affect and Optimism

- Our mood/emotions affect our judgement:
  - Mayer et al (1992): positive mood increases frequency estimates for positively-valenced events, negative mood increases frequency estimates for negatively-valenced ones
  - Implications for health communication
- Optimistic bias – people tend to believe that they are less likely to experience negative events than other people (experiments have shown this for heart attack, cancer, alcoholism etc)
  - May not take precautions to protect themselves
  - Depends on the comparison standard, perceived control of the risk, nationality, job status, self-esteem etc


KEEP
CALM
AND
CARRY
ON

Communication and Trust

- Process of communication often more important than fine-tuning words
- Messages often judged by source, rather than content – if source isn't trusted, good delivery may be *counterproductive*
- Trust is fragile
- Trust is multifaceted – perceived competence, objectivity, fairness, consistency, goodwill
- Statements about trust may not match actual responses
  - E.g. trust in government sources

Trust in sources

- Manis et al (1996):
  - 3000 Residents of Norwich, East Anglia
  - Vast majority distinguished between 'trustworthiness' of sources when seeking reassurance of risk
    - 8% trusted government (and by implication government scientists)
    - 12% trusted private companies
    - 15% trusted the media
    - Less than 33% trusted religious organisations and trades unions
    - 80% trusted friends
    - 90% trusted family

Social Amplification of Risk

- In communication, risk events and characteristics portrayed through 'risk signals'
- Signals undergo predictable transformation as they are filtered through 'amplification stations'
  - Increase/decrease in volume of information
  - Selectivity
  - Misinterpretation/elaboration of signals
- Accounts for 'ripples' of secondary consequences
  - market impacts, calls for regulatory constraints, litigation, community opposition, loss of trust
- But NB: suggests an underlying model of communication as 'one way'


NOW
PANIC
AND
FREAK
OUT

BSE/CJD Case Study

- Bovine Spongiform Encephalopathy (BSE) identified by MAFF November 1986
  - Affects the brain, leading to confusion, loss of motor function and death
  - By 31 October 1996: 164,000 confirmed cases in GB, 1700 in Northern Ireland, scattering elsewhere
  - Cause believed to be scrapie-contaminated meat and bonemeal from sheep fed to cattle
    - July 1988 – slaughter of all infected/potentially-infected cattle
    - Continued to be legal to feed MBM to cattle for human consumption until November 1989; in other animals, until September 1990
    - December 1995 – ban on use of mechanically-recovered meat from bovine vertebral column in human food
    - April 1996 – bovines > 30 months old and heads from all cattle over 6 months old excluded from all food or feed chains

Progress of the Epidemic

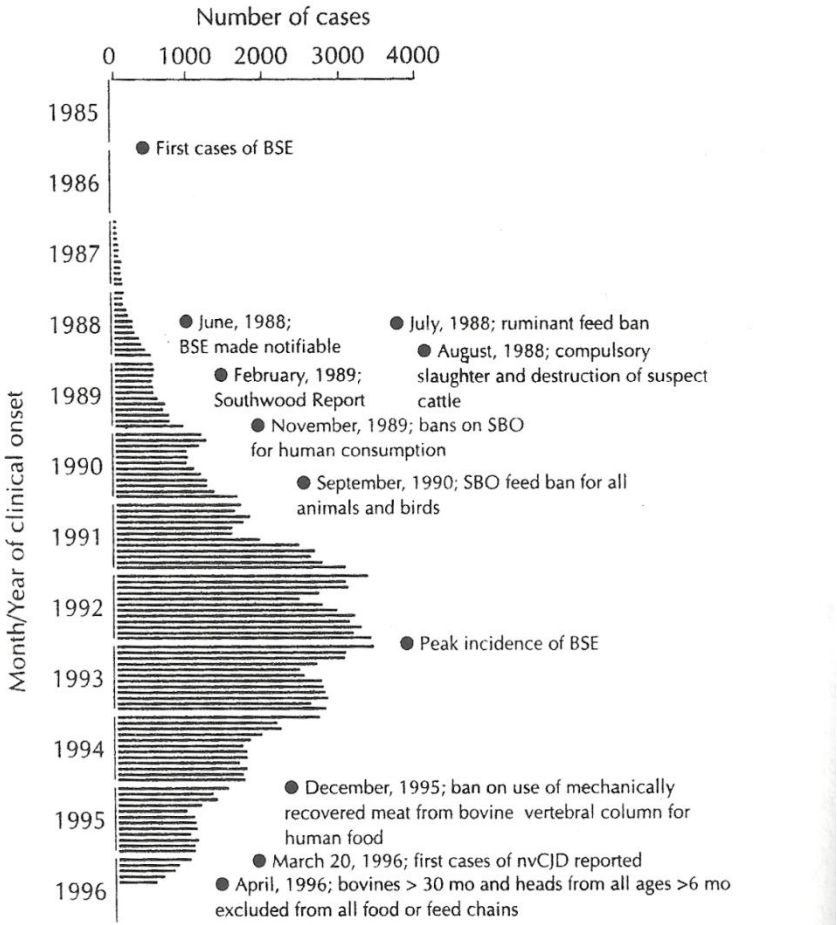

Fig. 7.1 Confirmed cases of BSE by date of clinical onset, 1986 to May 1996. (From Collee and Bradley (1997).)

Source: Bennett and Calman (2001), from Collee and Bradley (1997)

Attempts to curtail panic

May 6th 1990

"any risk [to humans] as a result of eating beef or beef products is minute. Thus we believe that there is no scientific reason for not eating British beef and that it can be eaten by everyone"
Dr David Tyrrell (Chair of Spongiform Encepalopathy Committee) in an open letter to the Chief medical Officer, 24th July 1990

New-Variant CJD

- Creutzfeld-Jakob Disease – main form of Transmissible Spongiform Encephalopathy in man
- Non-variant form occurs sporadically throughout the world: about one case per 2 million people each year
- March 1996: British Government alerted to an article in *The Lancet* on ten cases of a new variant
  - All in the UK
  - Neuropathology similar to BSE
- Possible link between BSE and NVCJD announced in Commons on Wednesday 20th March 1996

Effects of the Crisis

- Deaths of almost 100 UK citizens from NVCJD (to 2001)
- Devastating economic effects on British beef industry
  - EC export ban
  - Enforced cull (millions of cattle)
- Knock-on effects for the meat-processing industry and for EC beef industry
- Political impact
  - British relations with Europe
  - Public faith in ability of 'society' (i.e. scientific community, government) to cope with scientific and technological innovation (in this case, intensive farming methods)
  - Public faith in government statements about food safety
  - Perceptions of cheap food and food traceability

Errors in communication

- MAFF/Government seen to be reacting to events
  - Initially slow to bring in measures, then come in thick and fast in response to the panic
  - Later, seem to overreact
    - Scale of culls go way beyond the scientific advice
- Scientists get perilously close to 'no risk' statements; Sec of State December 1995 described risk to humans as 'inconceivable'
- MAFF given control of food safety as well as improving agricultural efficiency
  - They gave too much credence to intensive methods
- Little research promoted to investigate the alternative hypothesis (i.e. cattle -> human transmission via food)
  - Accusations of 'scaremongering'

Risk and Acceptability

- Calculating the probability of danger concentrates on what's 'out there'
- Acceptability depends on what's 'in here'
- Never enough to assume that the science of risk is *only* about objective measures of external danger
- Throughout BSE crisis, those in authority in government and science tended to be robust in their perception of the acceptability of a low risk of danger
  - Couldn't understand people for whom such a risk, though low, is unacceptable

Conclusions (from experience, not all of it medical!)

- Risk communication in the medical domain a nexus of subtle and complex dimensions:
  - Emotions: disbelief, anxiety, denial, relief, hopefulness, concern, gratitude, panic
- Trust (in strangers) is hard-won:
  - Organizational 'body language'
    - Fatal to appear to be responding to events/acting only under pressure
  - Messages deliberately sent are only a minor part of the messages received
- Trust reinforced by openness
  - Candid accounts of the evidence, the possibilities, how the evidence is used in decision-making, uncertainties etc. build confidence
  - And by an acknowledgement of the intelligence/robustness of the patient (within limits!)
- Information without knowledge can be dangerous
- Response to the message depends on the content and the manner of the delivery
  - To engage with an outraged audience, you have to acknowledge the outrage

Implications for HISE

- We are increasingly likely to have to communicate with non-specialists
  - Technological risk may have an emotional, moral etc side
  - The language we use matters – "acceptable risk"
    - And 'bare rationality' may not be appropriate
  - People might not 'get' numbers…
    - Especially numbers like 1×10^{-9}
  - We can't assume that people will trust our numbers:

"If a guy tells me the probability of failure is 1 in 10^5, I know he's full of crap"

(Richard Feynmann, reporting that engineers' estimates of O-ring failure on Challenger were 1 in 200, while NASA publicised 1 in 10^5)