Introduction

Medicine is a less exact science than many believe; it is fraught with a myriad of uncertainties that can make decision making in women with breast cancer, or women who are at high genetic risk for it, very difficult. Even the best information available may be inadequate, with limited data about effectiveness or trade-offs between benefits and harms. The quality of any evidence concerning treatment risks is ultimately dependent on the veracity of good clinical trial data, followed by careful and comprehensive systematic monitoring of therapeutic endeavours in the clinic. All decisions women may make, from consenting to diagnostic tests, choice of surgery or systemic treatments, to consideration of lifestyle changes, are made on the basis of implicit or explicit judgements about the risk or perceived benefit/harm ratios. Patients must consider their own personal risk for either developing breast cancer and/or having a recurrence of their disease, and then balance these risks against the harms and benefits of various screening procedures or treatments. Inaccurate risk perceptions may lead to suboptimal decision making, so all health care professionals need to be aware of the impact that their own communication may have on patients' understanding and on some of the psychological issues that influence the lay populations' beliefs and behaviours.

Numeracy and understanding of risks

Research shows that innumeracy affects both sexes and that most lay populations lack the minimal skills needed to interpret health education materials. Surprisingly, this is not just a matter of education, because even among educated samples fewer than half were able to convert a proportion such as 1:1,000 to a percentage (0.1%) and only 70% could convert 20/100 into a percentage [1].

There is a vast difference between the estimated magnitude of certain risks, perceptions, interpretations, acceptance of these and subsequent behaviours. Telling an individual that they have a risk of 1.3 in 10,000 compared with a general population risk of 1 in 10,000 does not concern most people, whereas saying that they have a 30% greater risk than the average person of succumbing to a disease is perceived as very risky, even though both statements are the same. A further difficulty for lay populations is that inherently probabilistic risk information is often converted into definitive or declarative statements that can influence decision making about screening or treatment.

Absolute and relative risks

Many of the new treatments for breast cancer can look much better than the standard therapy, depending on how they are described. A 50% reduction in recurrence is not so impressive when it is pointed out that this only applies to the 5% who actually stood to gain any benefit from the drug. Absolute and relative risks are extremely difficult for lay populations to grasp. Even more troubling is the fact that many health care professionals themselves find the differences between absolute and relative risks difficult to understand and explain [2].

Decision-making

We like to think that before making a decision about any form of treatment or screening women will first assemble all of the possible information provided by doctors, specialist nurses and others, consider these and make an option appraisal of the costs and benefits, and finally make a rational choice. However, many factors will influence this, including the personality characteristics of a woman, her anxiety state, her preconceived ideas and expectations, and how the facts have been presented. Real-world decision makers are rarely rational - they may use unreliable sources of information, use minimal heuristics to simplify the facts and figures, and find solutions that provide a fit with these.

Risk appraisal and understanding probabilities

There have been many studies published since the seminal work of cognitive psychologists Tversky and Kahneman [3], which showed that both lay people and trained health care professionals who are familiar with statistics use minimal heuristics to simplify situations. People often dichotomize...
actions, behaviours and treatments into polar extremes, such as 'safe/dangerous' or 'good/bad'. Thus, vitamins may be seen as good things, although we know that overdosing can kill. Likewise, many people, not just idealistic vegans and vegetarians, see meat as bad despite its nutritional benefits. Another important aspect of irrational or faulty risk appraisal is that judgements are made independent of dose, so for example oxygen is seen as good, despite the fact that 100% can be extremely harmful in some respiratory conditions or when given to premature babies. Lay populations also tend to put too much emphasis on anecdotal but familiar experiences, such as the apocryphal friend or relative who smoked 60 cigarettes a day and drank every night but still lived until their 90s without a day off work.

Communication about probabilities is made even more complicated by the fact that people prefer absolutes, for example 'without an operation death is certain' or 'this treatment is completely safe' [4].

Some of the common errors seen include a general failure to understand that probabilities in a set must include all possibilities; in other words, for a high-risk woman contemplating mammographic screening, the percentage chance of finding a cancer and the chance of a cancer being absent must add up to 100%. Few appreciate that probabilities of independent events must be multiplied not added. Conditional probability reasoning is another common confusion; the conditional probability of event X given event Y is not necessarily equal to the probability of event Y given X. The probability of breast cancer in a patient with BRCA1 or BRCA2 gene mutation is around 70%, but the probability that a woman with breast cancer also has the gene mutation is substantially lower.

Observations of lay populations' use of figures show that a term such as 50% may be used in rather non-numeric terms, indicating just general uncertainty, a lack of precision, something that may or may not happen.

Probabilities are often just too abstract for understanding and/or decisions. Few of us could say what 1:100,000, for example, means in relation to other common risk behaviours. In fact the risk for being murdered is 1:100,000, death playing soccer 1:50,000, and dying in a road accident over a 50-year period of driving 1:85. The 'risk' for getting three balls in the UK National Lottery is 1:11 [5], which is rather similar to the lifetime risk of getting breast cancer.

Although we have an understanding of all of these events and the ability to quote the statistics given, perceptions of personal vulnerability to them differ widely and may be complicated further by framing effects.

**Framing effects**

Context in everyday life influences our perception of sight, smell and sound. An aroma subjected to a person shown a picture of a French restaurant and a trolley of interesting cheeses provokes a neutral or pleasing response; that same aroma applied when people are shown a photo of dirty laundry, in particular socks, produces revulsion. Likewise, context and framing affect thinking and decision making. Take a hypothetical example of 100 patients with lung cancer that could be treated either by surgery or radiotherapy. The information could be framed in terms of survival - 90 patients will live through the surgery and 34 will still be alive at 5 years. It could also be framed in terms of mortality - 10 patients will die during surgery and a further 56 will be dead within 5 years. Surgery is seen as a less attractive option when mortality framing is used, and these effects are as large with physicians as with lay people. Some consequences of this are that treatments, including chemoprevention, may be accepted or rejected on the basis of the way in which they are framed. Advertisers are well aware of these facts and manipulate their presentation of data accordingly.

**Implications for women at high risk for breast cancer**

A woman at high genetic risk for breast cancer has essentially four options: do nothing, engage in regular surveillance and screening, undergo bilateral prophylactic mastectomy (BPM), or enrol in a chemoprevention trial. These options have fairly major implications, and good quality genetic counselling is crucial to ensure that decisions are made based on the best quality information and true appreciation of the potential harms, as well as an understanding of the putative gains and risk reduction.

Some interesting results were seen in a quantitative [6] and qualitative [7] study of 143 women with risk levels between 1:2 and 1:4 who were offered BPM. Seventy-nine women opted for surgery, 64 chose regular surveillance and 11 deferred any decision. Most women could quote verbatim what they had been told about risk, but women choosing surgery perceived their individual risk to be much higher than those declining it (P < 0.005). Significantly more women opting to undergo surgery thought it inevitable that they would develop breast cancer (32% versus 10%; P < 0.003). Typical quotes demonstrating this perception included “… it’s not a case of if I get it (breast cancer) but when’. Others had been powerfully influenced by identification with their dead mothers; ‘My mother died when she was 34 and my sister when she was 32. I’m 34 next year so I want the surgery’ or ‘I know that they said it isn’t certain that I will get it too but I’m the one who looks like my mother.’

When psychological morbidity of the women was examined some further differences emerged. The high anxiety and depression seen before surgery declined at 6 months and 18 months in those who opted for BPM, whereas psychological morbidity did not change over time for women choosing surveillance. Personality differences between the two groups of women offered some explanation for the
resolution of some morbidity amongst the surgical group but little in the decliners. Those opting for surgery were more likely to have problem-focused coping characteristics ($P=0.03$), whereas the surveillance group were more likely to use detachment as a coping strategy ($P<0.001$). Furthermore, the decliners had higher anxiety traits than the acceptors. Consequently, the more problem-focused acceptors of BPM felt a relief of some of their anxiety after surgery, but the decliners who tried to adopt a more ostrich-like ‘head in the sand’ approach to things found that the regular check-ups and surveillance maintained their anxiety, because they could not employ detachment with the constant reminders of their high risk.

**Conclusion**

An understanding of the risks from breast cancer as well as the potential harms of treatment are vitally important to ensure appropriate decision making. There is little evidence, even after genetic counselling, that high-risk women have an accurate understanding, with personality and other factors influencing perception and decisions. Health care professionals must ensure that they themselves are not being influenced by framing effects and the presentation of data before trying to communicate treatment options to patients. Finally, more research is needed into interventions that make communication about risk both easier and more accurate [8].

**Competing interests**

The author declares that they have no competing interests.

**Acknowledgement**

This article has been published as part of *Breast Cancer Research* Volume 10 Supplement 4, 2008: Controversies in Breast Cancer 2008. The full contents of the supplement are available online at http://breast-cancer-research.com/supplements/10/S4

**References**

1. Lipkus IM, Samsa G, Rimer BK: General performance on a numeracy scale among highly educated samples. *Med Decis Making* 2001, 21:37-44.
2. Girgerenzer G, Edwards A: Simple tools for understanding risks: from innumeracy to insight. *BMJ* 2003, 327:741-744.
3. Tversky A, Kahneman D: Judgment under uncertainty: heuristics and biases. *Science* 1974, 185:1124-1131.
4. Politi MC, Han PK, Col NF: Communicating the uncertainty of harms and benefits of medical interventions. *Med Decis Making* 2007, 27:681-695.
5. Adams AM, Smith AF: Risk perception and communication: recent developments and implications for anaesthesia. *Anaesthesia* 2001, 56:745-755.
6. Hatcher MB, Fallowfield L, A’Hern R: The psychosocial impact of bilateral prophylactic mastectomy: prospective study using questionnaires and semistructured interviews. *BMJ* 2001, 322:76.
7. Bebbington Hatcher M, Fallowfield LJ: A qualitative study looking at the psychosocial implications of bilateral prophylactic mastectomy. *Breast* 2003, 12:1-9.
8. Lipkus IM: Numeric, verbal, and visual formats of conveying health risks: suggested best practices and future recommendations. *Med Decis Making* 2007, 27:696-713.