THE RISK OF TREATMENT. A STUDY OF RHEUMATOID ARTHRITIS PATIENTS' ATTITUDES

M. HO, B. LAVERY AND T. PULLAR
Rheumatic Diseases Unit, Ninewells Hospital, Dundee DD1 9SY

SUMMARY
Despite its importance, there is no well-validated method of measuring patients’ concept of ‘acceptable’ risk of medical treatment. Numerical methods give widely varying results depending on the methodology. We have attempted to assess ‘acceptable’ risk using relative comparisons. We administered a questionnaire to 67 patients with rheumatoid arthritis (RA). In general, patients’ estimate of acceptable risk was less than the actual risk of treatment. Some illogical choices were made, showing poor understanding by patients of the concepts of risk and risk:benefit ratio. Patients appeared willing to accept higher levels of risk from procedures than from drug treatment. Willingness to accept risk in exchange for successful treatment of their RA did not correlate with disease severity, age, willingness to take non-medical risks or family responsibilities.

Key words: Rheumatoid arthritis, Treatment, Risks, Attitudes.

The concept of risk:benefit ratio is central to medicine. It is also increasingly recognized that patients should be aware of the risks of medical treatment [1, 2]. Other factors, such as the patient’s prior perception of risk, may be important in the patient’s overall perception of the risk from a particular treatment [3, 4]. In his Heberden Oration, Sir Kenneth Calman highlighted the importance of understanding perception of risk and communicating risks of treatment to individuals and to the public [2]. Previous work has shown that what patients, and also doctors, regard as an acceptable risk of drug treatment may be unrealistic [5] and is dependent on methodology [5–7]. In an attempt to overcome the latter problem, we have attempted to assess ‘acceptable’ risk to patients of drug treatment using a descriptive, relative, non-numerical scale, avoiding the requirement for patients to attempt to relate to a numerical scale.

PATIENTS AND METHODS
Sixty-seven patients with rheumatoid arthritis (RA) attending our clinic were studied. Patients were chosen from the clinic at random. The questionnaire consisted of a series of 18 cm horizontal logarithmic scales with 2 cm divisions, marked at one end ‘almost impossible’ and at the other ‘certain death’. Further descriptors were inserted along the scale, e.g. risk of being struck by lightning. The extremes of the scale represented risks of $10^0$ and $10^9$. Each scale represented the probability of death as an adverse effect which the patient would regard as acceptable for certain potentially beneficial situations. The potentially beneficial situations given were: complete cure of their arthritis, 30% improvement in symptoms, prevention of further deterioration and total hip replacement. Patients were also given the scenario of having intractable angina pectoris and asked about the acceptable risk of coronary angiography. Patients were also asked what they would regard as an acceptable risk of flying to a foreign holiday destination and of being a regular cigarette smoker. Risk is reported as safety degree units (SDUs) [4], which represent the log of the reciprocal of the numerical risk, e.g. $1/1000$ risk $= \log 10^3$ SDU $= 3$ SDU. Non-parametric statistics were used. Details of age, sex, disease duration, current drug treatment, pain score, Stanford Health Assessment Questionnaire (HAQ), smoking habits and family responsibilities (marital status and number of dependant children) were also recorded.

Approval was obtained from the Tayside Committee on Medical Research Ethics.

RESULTS
Forty-nine females and 18 males were studied, 19 were smokers, two ex-smokers and 45 non-smokers, one whose smoking history was not recorded. The median age was 57 yr (range 15–80) and median disease duration was 10 yr (range 1–30).

Patients’ views of acceptable risk are shown in Table I. Patients were willing to accept a greater risk of death for complete cure of their RA than for 30% improvement (Wilcoxon $P = 0.04$). However, patients were no more willing to accept death as an adverse effect of drug treatment offering complete cure than they were as an adverse effect of total hip replacement (Wilcoxon $P = 0.058$) and, paradoxically, were more willing to accept death from a total hip replacement than from a drug treatment offering 30% overall improvement (Wilcoxon $P = 0.04$). ‘Complete cure’ of arthritis was seen as more risk worthy than going on a foreign holiday (Wilcoxon $P < 0.001$), but less so than undergoing a coronary angiogram (Wilcoxon $P = 0.04$). Furthermore, on 21 occasions, patients appeared willing to accept a greater probability of death for a lesser drug-related therapeutic outcome, e.g. would accept a greater risk for ‘no deterioration’ than for ‘30% improvement’. Willingness to accept the risk of travelling to a foreign holiday destination did not predict the level of risk accepted for therapeutic

Submitted 28 July 1997; revised version accepted 7 October 1997.
Correspondence to: T. Pullar.

© 1998 British Society for Rheumatology
<table>
<thead>
<tr>
<th>Benefit</th>
<th>Median (range) risk of death accepted (SDU)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Complete cure</td>
<td>5.0 (1.3–9.0)</td>
</tr>
<tr>
<td>30% improvement in symptoms</td>
<td>6.0 (1.4–9.0)</td>
</tr>
<tr>
<td>No deterioration in symptoms</td>
<td>6.0 (1.4–9.0)</td>
</tr>
<tr>
<td>Hip replacement</td>
<td>4.6 (1.0–8.7)</td>
</tr>
<tr>
<td>Coronary angiography</td>
<td>4.2 (1.0–9.0)</td>
</tr>
<tr>
<td>Travel to foreign holiday destination</td>
<td>6.7 (0.3–9.0)</td>
</tr>
<tr>
<td>Smoking</td>
<td>8.0 (0.7–9.0) (median 3.5 for smokers, 6.8 for non-smokers)</td>
</tr>
</tbody>
</table>

outcome. No relationship was seen between the level of risk accepted and disease duration, pain score, HAQ, current or past drug treatment, number of dependent children or [except for the risk of smoking itself (P < 0.0001)] smoking status (Spearman rank all P > 0.05).

**DISCUSSION**

Using this method, the ‘acceptable’ level of risk was lower by a factor of ~25–40 than the real risk of current drug therapy [8]. This compares with our previous study using a different method where the ‘acceptable’ level of risk differed from the actual level by a factor of ~10,000 [5] and also from studies [6, 7] using a standard gamble technique, where a 20–27% risk of death appeared acceptable. Although this study avoided presenting patients with a numerical choice, when converted into numerical risks subsequently the low level of ‘acceptable’ risk still seems unrealistic for currently available treatments. It is clear that we lack a gold standard against which we can measure different methods of assessing acceptable risk. One of the major findings from this study remains the difficulty which patients experience with the concept of risk and benefit, with a sizeable proportion of illogical choices being made. In particular, patients appeared to have difficulty with the concept of ‘no deterioration’ compared with ‘improvement’, which is a common concept to most doctors. It would also appear that because patients expect, or perhaps understand better, risks from surgical procedures, they are more willing to accept these even where the benefit (again perhaps perceived by patients to be better understood) is less than with a drug treatment. We were also unable to demonstrate any relationship between what might be regarded as indicators of risk-taking behaviour, i.e. acceptable risk of foreign travel, smoking habits and family responsibilities, and the level of risk deemed acceptable from medical intervention. Although we did not formally enquire about previous adverse drug reactions, several patients did mention that they had experienced reactions, but there appeared to be no consistent effect of this on the level of risk acceptable from drug treatment. Overall, it seems that patients with RA have a poor understanding of risk and of risk:benefit ratios. This is likely to be especially so when these relate to drug treatment.

**REFERENCES**