

Shared decision-making based on different features of risk in the context of diabetes mellitus and rheumatoid arthritis

Monica Ortendahl

Royal Institute of Technology,
Stockholm, Sweden

Abstract: There is an increased awareness about patients' involvement in the clinical decision process where uncertainty is an unavoidable condition. The impact of psychological factors like risk aversion, risk aversion and time, asymmetry in risk aversion, and risk and control on shared decision-making is discussed. In addition to differences in risk estimates, doctors and patients may exhibit a difference in perception of time perspectives, and losses versus gains.

A summary of valuation factors in shared decision-making is presented: (a) the doctors tend to follow expected value combinations more closely, while the patient is more risk averse; (b) unwillingness to take risks increases for rare outcomes; (c) there is an increased tendency to take risks with delayed outcomes of the decisions; (d) the doctor is generally well informed about risk and time aspects for different diseases, whereas this might not always be the case with the patient; (e) rheumatoid arthritis and diabetes mellitus are chronic diseases, and both create a vulnerability to a variety of complications over time; (f) rheumatoid arthritis demands different combinations of treatments sequentially over time, whereas diabetes mellitus is treated with insulin; (g) many diseases, like rheumatoid arthritis and diabetes mellitus, are not completely affected by control, as the disease may constantly progress.

Keywords: shared, decision-making, risk, aversion, time, control

A 60-year-old female has had rheumatoid arthritis for 20 years, and has been treated with methotrexate for 5 years. Initially the effects of the treatment were positive, with decreased pain and disability, but now the treatment experience of the drug is not satisfactory. Moreover, the side effects concern the patient. Now a decision has to be made once again about what treatment to continue with.

A 20-year-old male in recent months has noted increased frequency of urination, excessive thirst, increased appetite, and weight loss. Moreover, he has noticed decreased energy and fatigue. He has previously been in good health. When he consulted a doctor, a HbA1c of 9 percentages was found, and he was diagnosed with a type 1 diabetes mellitus. He is now treated with insulin and has been given information about diet and exercise. A type 1 diabetes mellitus requires that the insulin dose always has to be monitored and adjusted. HbA1c is controlled, and a decision now has to be made about whether the insulin treatment has to be adjusted.

These are common scenarios in clinical practice. From this perspective a central goal is informed and shared decision-making in treatment judgments and choices. Actual clinical practice is not just a one-time decision for which informed consent is required, but a series of decisions that are part of an ongoing relationship. There is an increased awareness now about patients' involvement in the clinical decision process, where patients and providers consider outcome probabilities and patient

Correspondence: Monica Ortendahl
Malma Backe 3 H, 756 47 Uppsala,
Sweden
Tel +46 18 302549
Fax +46 650 723 9656
Email monicaortendahl@hotmail.com

preferences (Montgomery and Fahey 2001; Siminoff and Step 2005). Decision research, following the tradition initiated by Tversky and others (Tversky and Kahneman 1986), has recognized expected value and probability of outcome in explaining judgments and decisions in various domains, and as being based on the products of these two parameters; the study of this is addressed by what is termed expected value of information (EVI) theory (Ades et al 2004). As Tversky and others have noted, actual practice in the face of uncertainty is usually an iterative approach, grounded initially in a heuristic method of trial-and-error and evaluation (Kahneman and Tversky 1996).

Risk-related problems occur with treatment judgments and decisions, and uncertainty is an unavoidable condition in efforts to build a consensus about the preferred treatment (Edwards and Elwyn 2001a; Hall 2002). A decision will often have to be made about when, rather than whether, to undertake a risk-reducing treatment. There is evidence that with greater levels of informed choice, adherence to treatment chosen increases (O'Conner et al 1999; Arora et al 2005).

It is important that risk information be presented as something to be used as a sound basis for clinical decisions, for risk is not an easy concept (Iverson 2001). Information about both absolute and relative risk should be included, as they are perceived differently (Edwards and Elwyn 2001b). Absolute and relative risks, however, are statistical concepts, and further problems arise when doctors' and patients' psychological estimates of risk constitute the basis on which to build a consensus in order to implement a treatment (Loewenstein et al 2001).

The aim of the present paper is to discuss features of risk that are of importance for reaching consensus in shared decision-making applied to diabetes mellitus and rheumatoid arthritis. There is a current need in risk information to understand the impact on shared decision-making of psychological factors like risk aversion, risk aversion and time, asymmetry in risk aversion, and risk and control.

Risk aversion

Risk aversion theory implies that one prefers the expected value, whereas risk seeking connotes that one prefers a gambling situation with an uncertain outcome of choice (Cher et al 1997). Individuals generally are risk averse (Rosen et al 2003; Wakkar 2004). It could be speculated that patients are more risk averse, as the outcomes of decisions have a greater impact on them. It is their body, and their life, that are affected by the treatment. Perhaps the doctors tend

to follow expected value combinations more closely, while the patients are more risk averse.

However, applying expected value combinations could be a problem for the doctor. With health outcomes, for example years of life gained, risk aversion is increased if benefits are nontransferable (Hoel 2003). In the judgment process the non-tradable risk must be accounted for in some way. One suggested solution (Salomon and Murray 2004) is the use of different measures of health that incorporate risk aversion or risk preference as to remaining life years or quality-adjusted life years.

This is information that has to be presented in a meaningful way by the doctor to the patient, indeed not an easy task. When outcomes are calculated without taking risk into account, treatment choices will be overvalued. When they are compared with the more risky alternative, however, certain treatments might be undervalued (Breslow 2003). Thus, because some treatment programs may be undervalued due to a net reduction in risk, the factor of risk should be taken into consideration in clinical decision-making by both the doctor and the patient.

Bayesian studies on information processing in judgments have shown that unwillingness to take risks increases for rare outcomes (Elstein 2004). Are medical outcomes perceived as rare by both doctor and patient? Perhaps what is rare for the patient is not rare for the doctor. Risk willingness thus might differ between the doctor and the patient due to different perspectives on risk features and decision-making.

Risk aversion and time

Further complexities arise in reaching an agreement on treatment, when the relationship between risk aversion and time aspects is considered. An increased tendency to take risks has been found when outcomes of the decisions are delayed (Watt 2000; Hojgard et al 2002). A tentative explanation is that a time discounting effect, lowering the estimated probability for the occurrence of distant outcomes, is operating here (Ortendahl and Fries 2006). So far, there has not been much focus upon time aspects in shared decision-making. Perhaps the time perspective of the doctor is different from the time perspective of the patient, both objectively and subjectively. The doctor is generally well informed about risk and time aspects for different diseases, and this is not always the case with the patient.

Decision-making is often driven by the overwhelming impact of the acute medical problem on all aspects of the individual's life. With chronic conditions, patients must make multiple and repetitive decisions, with variable

outcomes, about how they will live with their chronic condition. Both rheumatoid arthritis and diabetes mellitus are chronic diseases. Symptoms of rheumatoid arthritis are persistent joint pain which is aggravated by movement or activity such as walking, getting up from a chair, holding an object. There is an inflammation, indicated by joint swelling, stiffness, redness, and warmth, which destroys cartilage, bone, and ligaments, leading to possible deformity and disability.

Diabetes mellitus is a group of metabolic disorders with one common manifestation: hyperglycemia. Symptoms of type 1 diabetes are increased thirst, increased urination, weight loss in spite of increased appetite, fatigue, nausea, and vomiting. Diabetes creates a vulnerability to a variety of complications over time. Control of blood sugar is the best way to minimize the risk of complications, but the risk of complications increases with the length of time the patient has had the disease. Diabetes complications affect the eyes, kidneys, nerves, and large and small blood vessels.

These complications could occur at different points of time. Moreover, changes could occur in judgments over time for both the doctor and the patient. Risk aversion can decrease or increase over time as the patient gains more experience with a chronic illness. The patient has to live with the risk that the disease might progress, and that the effectiveness of the treatment decreases over time. For a patient with type 1 diabetes the risk and uncertainty could vary in the course of the same day, as the blood glucose level varies with the amount of exercise and the food intake. For type 1 diabetes the treatment is to take insulin, but the dosage may vary.

Rheumatoid arthritis might demand different combinations of treatments sequentially over time. Depending on symptoms, treatment chosen could be conservative, involving aspirin or one of the NSAIDs. In a more aggressive treatment methotrexate could be added to the regimen. Other treatment options are steroids and Plaquenil (Tsakonas et al 2000). There are numerous other treatments which are used in conjunction with one another, or alone, that manage the disease for patients with mild or moderate disease (Doan and Massarotti 2005). Beyond that, a newer class of drugs known as TNF blockers could be prescribed (Coenen et al 2007). Exercise programs, physical therapy and surgery are complementary treatments. For rheumatoid arthritis the expected value of a specified treatment could be estimated for different periods, with the traditional decision-making paradigm repeated for different periods (Ortendahl et al 2000). The optimizing of sequences of medical treatments

is another issue related to risk and time that needs further attention.

With regard to issues of risk and time in relation to health behavior, a study of smokers who had failed in their attempt to quit smoking found that their level of perceived risk declined over time (Gibbons et al 1991). While the situation of patients with a disease differs from that of people confronting preventive procedures, it could be contended that the study's finding has an application in the domain of treatment. That is, in order to maintain motivation and compliance with the chosen treatment of a disease, information on medical decision-making should be framed to counteract the tendency for risk perception to decline.

Asymmetry in risk aversion

The salience of both negative and positive consequences has been found to diminish with distance to the goal, though in fact the saliency decreases faster for negative outcomes (Berndsen and van der Plicht 2001). Moreover, an earlier study found an asymmetry in risk aversion (Kahneman and Tversky 1979), with a preference for certain over uncertain gains, whereas for losses uncertainty was preferred to certainty.

When applied to health behavior and shared decision-making, such an asymmetry may have importance, since the immediate action could give a loss with a high degree of certainty (Gyrd-Hansen et al 2003). For the individual patient the gain obtained in the future by treatment is uncertain, despite its being predictable for the patient population as a whole. Further problems, discussed previously (Ortendahl and Fries 2002), then arise related to gains and losses in treatment, as doctors and patients may perceive losses and gains in different ways, something that makes it more difficult to reach a high level of consensus.

Both rheumatoid arthritis and diabetes mellitus are chronic diseases demanding life-long treatments. Both carry a high risk of constant deterioration in health in several respects. The patient with type 1 diabetes has to maintain normal glucose levels and the patient with rheumatoid arthritis has to endure different medical regimens. Despite this strict treatment, the result might be only to lessen the slope of decrement, with a negative end result for the disease process itself. Deterioration from the disease is a loss; recovering from or avoiding the progression of the disease is a gain.

The treatment is necessary for medical reasons, and that necessity is the motivating factor for continuing treatment despite its adverse effects. Efficacy can then be regarded as a gain, and toxicity as a loss when treating a disease. Perhaps side effects like nausea or headache, for example, have a

larger impact on judgments and treatments chosen by the patient compared to the doctor.

Risk and control

Many diseases are not completely affected by control, as the disease may constantly progress. One example is cancer, which treatment might control only to some extent (Myers 2005). The patient can control a disease like type 1 diabetes to a larger extent by taking insulin, exercising and eating the right food. Rheumatoid arthritis is another disease that to some extent might be controlled through treatment with certain drugs in spite of its progress. Control over the progress of the disease is difficult to achieve, but the patient and the doctor might gain some degree of control over it by following certain treatments (Ortendahl et al 2000).

In the same study on rheumatoid arthritis a low retention rate in taking methotrexate was related to a high initial level of pain. One explanation for this result was that when a patient is in a poor state of health, every potential treatment might be tried with little patience. High level of pain is probably associated with high disease activity and severe disease. It is possible then that methotrexate is insufficient to manage the disease, and therefore more advanced, and perhaps even experimental or novel treatments need to be considered. The patience at issue might be both the doctor's and the patient's. The patient's because he or she does not like being unable to drink alcohol and feeling nauseated from the medication. Or the physician's, if there is an interest in pursuing a more aggressive therapy to get a faster result and reduce the risk of permanent joint deformity.

On the other hand, it might be easier to experience improvement with new drugs when patients are starting from a poor state of health, motivating them to continue the therapy, and yet this was not the case. The result could also be explained by a discrepancy between doctors' prescriptions and the pain assessed by the patient, as the doctor might have based the treatment on other variables.

Thus, the study indicates the importance of communication and shared decision-making to increase compliance with the treatment chosen. The control perceived by the patient might increase when the patient is given information about the progress of the disease, the loss of health if the disease went untreated, and the gain if the treatment is complied with. Recent research on framing health information has indicated that compliance is affected by whether the information is framed as a gain or a loss (Ortendahl and Fries 2005). Having a disease is a situation in which

the patient is already in a loss situation; this makes the framing of messages more complex. A study by Armstrong et al (2002) found that stating chance of death over time resulted in lower levels of understanding and less interest in preventive surgery than framing statements as chance of survival over time.

Control might be achieved to a larger extent in preventive procedures. Through life-style choices, the patient can increase the probability of preserving health. If no disease develops where progress is beyond the control of the doctor and the patient, no treatment judgments and choices have to be made.

Implications for clinical work

Informed and shared decision-making is complex, and many issues have been raised in the present article (see Table 1).

How are sound treatment decisions determined? Are they based on value of the outcome, the probability of the outcome? Are judgments and decisions based on both variables or are simplifying strategies used based on only one of the variables?

The application of evidence-based medicine requires the combination of scientific facts with value judgments, and the cost of different treatments (Jenicek and Stachenko 2003; Saarni and Gylling 2004). This procedure could be approached from the perspective of doctors or of individual patients. Studies of medical decision-making usually provide information about the outcomes of clinical decisions but little information about the process of the decision (Teutsch 2003). Doctors may not value different aspects of health in the same way as patients, and studies on patient control have

Table 1 Valuation factors in shared decision-making

- The doctor tends to follow expected value combinations more closely, while the patient frequently is more risk averse
- Unwillingness to take risks increases for rare outcomes
- There is an increased tendency to take risks when decisions have delayed outcomes
- The doctor is generally well informed about risk and time aspects for different diseases, whereas this might not always be the case with the patient
- Rheumatoid arthritis and diabetes mellitus are chronic diseases, and both create a vulnerability to a variety of complications over time
- Rheumatoid arthritis demands different combinations of treatments sequentially over time, whereas diabetes mellitus is treated with insulin
- Many diseases, like rheumatoid arthritis and diabetes mellitus, are not completely affected by control, as the disease may constantly progress

found that patients generally respond positively to increased information (Auerbach 2000).

However, research in cognitive psychology has shown that people are quickly overwhelmed by having to consider more than a few options in making choices (Ubel and Loewenstein 1997). Therefore, decision analysis, based on the concepts of value and risk, provides a quantifiable way to choose between options and might be expected to facilitate clinical judgments and shared decision-making. Overall, likelihood of a specific adverse outcome should be a parameter affecting the estimate of future risk and its consequences. Risk estimates of future outcomes could be based on an outcome in the future having less importance than one in the present, and where the adverse outcome may have different values to the doctor and the patient.

Another parameter is temporal distribution of risk not being homogenous throughout the life-span of the individual. Specific individual factors modify the risk for a specific person, and person-specific modifiers are likely distributed differently in time. Severity of a disease may not be the same for everyone who experiences the disease. One example is occupational back pain being relatively mild in some persons but disabling in others (Staiger et al 2005).

Further complexities arise with decision analytic models applied to different diseases, like rheumatoid arthritis and diabetes mellitus. Rheumatoid arthritis gives different symptoms like pain and disability. Should pain or disability or both constitute the basis for the process of the decision, and the assessment of outcomes? What is the estimate of probability that one or both of the symptoms will decrease with the treatment chosen? How are pain and disability experienced subjectively by the patient? For the doctor disability is more apparent and objective, whereas the pain, which is subjectively experienced by the patient, might be more difficult to endure.

There is an ongoing discussion about complications or longer term consequences of the disease or of poorly managed disease. With rheumatoid arthritis, there is an additional level of complexity involving complications and risks associated with treatment, including methotrexate, steroids, and even anti-TNFs. This may be an additional wrinkle in the decision-making process, implying that treatment itself is not a cure-all, or close to it, with inherent risks.

Moreover, in rheumatoid arthritis the effectiveness of a drug may decrease after a period of time. In a study on the methotrexate therapeutic response (Ortendahl et al 2002) it was found that disability began to re-progress after 42 months, with a re-progression to baseline after 8 or more years. The treatment of rheumatoid arthritis implies a succes-

sion of single or multiple drugs with decision points where the next drug is chosen. Therefore, risks must be considered repeatedly in sequences.

For patients with type 1 diabetes the level of blood glucose measured by HbA1c is the basis for a decision to start a treatment with insulin. Other treatments like exercise and diet usually are not sufficient to regulate the blood glucose level. The treatment with insulin, which is life-long, decreases the risk of late complications, and HbA1c is regularly measured to assess the effectiveness of the treatment.

Final comments

From the discussion above, it is evident that there could be a discrepancy in risk estimates between the doctor and the patient, both objectively and subjectively, with an impact on the patient's compliance level to prescriptions and treatments. Therefore, features of risk should increasingly be stressed in clinical decisions based on mutual agreement (Feldman et al 2002; Fierz 2004).

The present article has initiated a discussion of what doctors and patients could do about risk-related aspects in health, and how risk dimensions of health should be taken into account in clinical decision-making. It is evident that introducing features of risk, like risk aversion, risk aversion and time, asymmetry in risk aversion, and risk and control, provides a more complete, if more complex, picture of clinical judgment analysis as a foundation for the doctor and the patient. It could be concluded that the process of attaining shared goals should be based on risk aspects and a realistic decision analysis. However, further research is required to understand the variations in doctors' and patients' risk preferences in shared decision-making.

References

- Ades AE, Lu G, Claxton K. 2004. Expected value of sample information calculations in medical decision modeling. *Med Decis Making*, 24:207–27.
- Arora NK, Ayanian JZ, Guadagnoli E. 2005. Examining the relationship of patients' attitudes and beliefs with their self-reported level of participation in medical decision-making. *Med Care*, 43:865–72.
- Armstrong K, Schwartz JS, Fitzgerald G, et al. 2002. Effect of framing as gain versus loss on understanding and hypothetical treatment choices: survival and mortality curves. *Med Decis Making*, 22:76–83.
- Auerbach SM. 2000. Should patients have control over their own health care?: empirical evidence and research issues. *Ann Behav Med*, 22:246–59.
- Berndsen M, van der Pligt J. 2001. Time is on my side: optimism in intertemporal choice. *Acta Psychol*, 108:173–86.
- Breslow NE. 2003. Are statistical contributions to medicine undervalued? *Biometrics*, 59:1–8.
- Cher DJ, Miyamoto J, Lenert LA. 1997. Incorporating risk attitude into Markov-process decision models: importance for individual decision-making. *Med Decis Making*, 17:340–50.

- Coenen MJ, Toonen EJ, Scheffer H, et al. 2007. Pharmacogenetics of anti-TNF treatment in patients with rheumatoid arthritis. *Pharmacogenomics*, 8:761–73.
- Doan T, Massarotti E. 2005. Rheumatoid arthritis: an overview of new and emerging therapies. *J Clin Pharmacol*, 45:751–62.
- Edwards A, Elwyn G. 2001a. Understanding risk and lessons for clinical risk communication about treatment preferences. *Qual Health Care*, 10 (Suppl 1):9–13.
- Edwards A, Elwyn GJ. 2001b. Risks – listen and don't mislead. *Br J Gen Pract*, 51:259–60.
- Elstein AS. 2004. On the origins and development of evidence-based medicine and Medical decision making. *Inflamm Res*, 53(Suppl 2):184–9.
- Feldman SR, Chen GJ, Hu JY, et al. 2002. Effects of systematic asymmetric discounting on physician-patient interactions: a theoretical framework to explain poor compliance with lifestyle counseling. *BMC Med Inform Decis Mak*, Nov 25:2:8.
- Fierz W. 2004. Challenge of personalized health care: to what extent is medicine already individualized and what are the future trends? *Med Sci Monit*, 10:111–23.
- Gibbons F, McGovern PG, Lando HA. 1991. Relapse and risk perception among members of a smoking cessation clinic. *Health Psychol*, 10:42–45.
- Gyrd-Hansen D, Kristiansen IS, Nexoe J, et al. 2003. How do individuals apply risk information when choosing among health care interventions? *Risk Anal*, 23:697–704.
- Hall KH. 2002. Reviewing intuitive decision-making and uncertainty: the implications for medical education. *Med Educ*, 36:216–24.
- Hoel M. 2003. Allocating health care resources when people are risk averse with respect to life time. *Health Econ*, 12:601–8.
- Hojgard S, Enemark U, Lyttkens CH, et al. 2002. Discounting and clinical decision making: physicians, patients, the general public, and the management of asymptomatic abdominal aortic aneurysms. *Health Econ*, 11:355–70.
- Iverson DC. 2001. Editorial. *Patient Educ Couns*, 45:83–6.
- Jenicek M, Stachenko S. 2003. Evidence-based public health, community medicine, preventive care. *Med Sci Monit*, 9:1–7.
- Kahneman D, Tversky A. 1979. Prospect theory: An analysis of decision under risk. *Econometrica*, 47:263–91.
- Kahneman D, Tversky A. 1996. On the reality of cognitive illusions. *Psychol Rev*, 103:582–91.
- Loewenstein GF, Weber EU, Hsee CK, et al. 2001. Risk as feelings. *Psychol Bull*, 127:267–86.
- Montgomery AA, Fahey T. 2001. How do patients' treatment preferences compare with those of clinicians? *Qual Health Care*, 10 (Suppl 2):139–43.
- Myers RE. 2005. Decision counseling in cancer prevention and control. *Health Psychol*, 24(Suppl 4):71–7.
- O'Conner AM, Rostom A, Fiset V, et al. 1999. Decision aids for patients facing treatment or screening decisions: systematic review. *Br Med J*, 319:731–4.
- Ortendahl M, Fries JF. 2002. Time-related issues with application to health gains and losses. *J Clin Epidemiol*, 55:843–8.
- Ortendahl M, Fries JF. 2005. Framing health messages based on anomalies in time preference. *Med Sci Monit*, 11:253–6.
- Ortendahl M, Fries JF. 2006. Discounting and risk characteristics in clinical decision-making. *Med Sci Monit*, 12:41–5.
- Ortendahl M, Holmes T, Schettler JD, et al. 2002. The methotrexate therapeutic response in rheumatoid arthritis. *J Rheumatol*, 29:2084–91.
- Ortendahl M, Schettler JD, Fries JF. 2000. Factors influencing length of time taking methotrexate in rheumatoid arthritis. *J Rheumatol*, 27:1139–47.
- Rosen AB, Tsai JS, Downs SM. 2003. Variations in risk attitude across race, gender, and education. *Med Decis Making*, 23:511–7.
- Saarni SI, Gylling HA. 2004. Evidence based medicine guidelines: a solution to rationing or politics disguised as science? *J Med Ethics*, 30:171–5.
- Salomon JA, Murray CJ. 2004. A multi-method approach to measuring health-state valuations. *Health Econ*, 13:281–90.
- Siminoff LA, Step MM. 2005. A communication model of shared decision making: accounting for cancer treatment decisions. *Health Psychol*, 24(Suppl 4):99–105.
- Staiger TO, Jarvik JG, Deyo RA, et al. 2005. Brief report: Patient-physician agreement as a predictor of outcomes in patients with back pain. *J Gen Intern Med*, 20:935–7.
- Teutsch C. 2003. Patient-doctor communication. *Med Clin North Am*, 87:1115–45.
- Tversky A, Kahneman D. 1986. Rational choice and the framing of decisions. *J Bus*, 59:251–78.
- Tsakonas E, Fitzgerald AA, Fitzcharles MA, et al. 2000. Consequences of delayed therapy with second-line agents in rheumatoid arthritis: a 3 year followup on the hydroxychloroquine in early rheumatoid arthritis (HERA) study. *J Rheumatol*, 27:623–9.
- Ubel PA, Loewenstein G. 1997. The role of decision analysis in informed consent: choosing between intuition and systematicity. *Soc Sci Med*, 44:647–56.
- Wakkar PP. 2004. On the composition of risk preference and belief. *Psychol Rev*, 111:236–41.
- Watt S. 2000. Clinical decision-making in the context of chronic illness. *Health Expect*, 3:6–16.