

Decisional role preferences, risk knowledge and information interests in patients with multiple sclerosis

Christoph Heesen^{*1}, Jürgen Kasper^{1,2}, Julia Segal³, Sascha Köpke^{1,2} and Ingrid Mühlhauser²

¹Department of Neurology, University Hospital Eppendorf, Hamburg, Germany; ²Department of Health Sciences, University of Hamburg, Hamburg, Germany; ³Senior Counsellor, CMH MS Unit, North West London Hospitals NHS Trust, London, UK

Objective: Shared decision making is increasingly recognized as the ideal model of patient–physician communication especially in chronic diseases with partially effective treatments as multiple sclerosis (MS). To evaluate prerequisite factors for this kind of decision making we studied patients' decisional role preferences in medical decision making, knowledge on risks, information interests and the relations between these factors in MS. **Methods:** After conducting focus groups to generate hypotheses, 219 randomly selected patients from the MS Outpatient Clinic register (n = 1374) of the University Hospital Hamburg received mailed questionnaires on their knowledge of risks in MS, their perception of their own level of knowledge, information interests and role preferences. **Results:** Most patients (79%) indicated that they preferred an active role in treatment decisions giving the shared decision and the informed choice model the highest priority. MS risk knowledge was low but questionnaire results depended on disease course, disease duration and ongoing immune therapy. Measured knowledge as well as perceived knowledge was only weakly correlated with preferences of active roles. Major information interests were related to symptom alleviation, diagnostic procedures and prognosis. **Conclusion:** Patients with MS claimed autonomous roles in their health care decisions. The weak correlation between knowledge and preferences for active roles implicates that other factors largely influence role preferences.

Multiple Sclerosis (2004) 10, 1–8

Key words: shared decision making; multiple sclerosis; role preferences; risk information; information interests

Introduction

Patient autonomy in medical treatment decisions is increasingly emphasized by health authorities and in medical literature.^{1,2} Multiple sclerosis (MS) seems predestined for research on the patients' role in medical decision as the controversy on the value of immune therapies is still ongoing.^{3–5} The conflicting evidence represents a typical condition in which, according to Charles,⁶ a shared decision making process between patient and physician would represent the ideal decision model. Recently, the need for balanced information and patient participation in MS decision making has been acclaimed by the NICE MS Management Guidelines for the UK.⁷

It is assumed that patients cannot express informed preferences unless they are given sufficient and appropriate information.² Carefully developed information about the prognosis of the disease and the effects of medications, i.e., the knowledge of risks are important prerequisites for decisional competencies. This evidence-

based information may lead to an autonomous participation in the decisional encounter with the physician.

It has been hypothesized that evidence-based risk communication increases the sense of control, alleviates anticipatory reflection and induces a reflection on personal values leading to a two way exchange between physicians and patients.^{2,8} A systematic review has shown that risk information reduces decisional conflicts and stimulates patients to be more active, although the effect on outcome of decisions is uncertain.⁹

There is increasing consensus, that patients' participation in medical decision making needs to be facilitated. But, the impact of the information status on patients' interpersonal roles in the decision process is not clear. Furthermore, MS patients' perception of their disease differs from the physicians' views as Rothwell *et al.*¹⁰ have shown. Mobility restrictions appear to be less worrisome to patients than to physicians, while with mental disability it is the other way round. Thus, patients might also have different views on prerequisites for decision processes than physicians.

Recent studies have outlined communication and information deficits in the care of patients with MS.^{11–14} Studies on patient information in MS have focused on diagnostic issues.^{15,16} Since immune therapies are now often started while the disease is at an early stage the question about the early need for information and its influence on decision processes becomes more urgent. On the other hand, at this early stage information may be

*Correspondence: Christoph Heesen, MD, Department of Neurology, University Hospital Eppendorf, Martinistrasse 52, D-20246 Hamburg, Germany.

E-mail: heesen@uke.uni-hamburg.de

Received 9 February 2004; revised 14 June 2004; accepted 14 July 2004

disturbing leading to an early overmedicalization. Relevance of the subject is also underlined by the fact that especially patients with unrealistically optimistic expectations might stop treatment early.¹⁷ Thus, knowledge has a direct impact on treatment adherence.

This study is part of a project about shared decision making (SDM) in MS supported by the German Ministry of Health. In this first study we looked at possible prerequisite factors for patient participation such as patients' role preferences, MS risk knowledge, perceived subjective knowledge level and information interests.

A pilot study¹⁸ with focus groups showed a paucity of knowledge about risks among 56 MS patients despite a preference of for active roles in medical decision making. Results depended on factors such as course of the disease and current medication. Subsequently we performed a survey among randomly selected MS patients with two different disease courses based on the following hypotheses: MS patients prefer active roles in treatment decisions and role preferences might correlate with measured and perceived knowledge. Degree of MS knowledge may depend on disease courses and whether patients are on immune therapies. And MS patients' weights of different areas of MS knowledge might place mental health and symptom alleviation higher than immune therapies.

Methods

Survey sample

Based on the findings of the focus groups¹⁸ we carried out a survey among 1374 patients from the MS Outpatient Clinic of the University Hospital Hamburg, Eppendorf who were registered in a database. According to the hypothesis that the disease course is a major determinant of the risk knowledge we included 100 randomly selected patients in each group, primary progressive (PP), and relapsing–remitting (RR) disease. In addition, all patients with a disease duration of less than one year were recruited.

All patients received a cover letter delineating the background and funding of the study and clarifying anonymous data protection policy. Survey letters contained the MS risk knowledge (MSK) questionnaire, an information interest questionnaire, a role preference scale,¹⁹ and a stamped return envelope. Furthermore, patients were provided with a risk information leaflet about one single pivotal interferon trial and a questionnaire on the perception of this information. Results of this part of the study will be presented in a separate publication. After 4 weeks patients who did not respond were contacted by telephone and a second copy was mailed if requested. Returned letters that for any reason did not reach their recipients were substituted by further randomly selected patients from the database.

Instruments

For the assessment of risk knowledge about prognosis and treatment we developed a 19-item MSK questionnaire as a multiple-choice instrument (see appendix). It was con-

structed by clinical experts of the MS Outpatient Clinic of the University Hospital Hamburg according to the guidelines relevant in risk communication^{2,8} with a focus on pharmacological MS treatment (i.e., steroids, interferons, mitoxantrone). Items were checked in a group of five patients for relevance and clarity. In particular, patients were asked for risk calculations filling in percentages. Items were collected and repeatedly checked by the physician team of the MS Outpatient Clinic and in the focus groups. Patients were also asked to rate their perceived level of knowledge (PLK) relevant to therapeutic decisions on a visual analogue scale.

A second questionnaire contained 30 possible information areas in MS. Information preferences were surveyed by patients being asked to choose ten personally most important out of these 30 information areas. Patients then had to rank these ten items by subjective relevance. Data were analysed by grouping single fields under headings: diagnosis and prognosis (three items), immune therapy (six items), management of symptoms (nine items), complementary medicine (four items), validity of MS studies (two items) and rehabilitation (six items). Ranking scores were calculated as an arithmetical mean of the item group.

Decisional role preferences were investigated by applying an authorized translated German version of the Control Preference Scale.¹⁹ The scale refers to five different interaction styles in the physician–patient encounter as for example described by Charles:⁶ a paternalistic style, a professional as agent style, a shared decision style, an informed choice style and a concept of pure autonomy (see Table 1 for overview).

Patients had to rank these styles according to their preferences. The theoretical construct of the five styles along a continuum from paternalistic to autonomous has been shown by Degner *et al.*¹⁹ as the best fitting model to their data.

A 12-item instrument was used to obtain MS demographic data.

Statistical analysis

For the 19 items of the risk knowledge questionnaire (MSK) a range or a selection of possible answers were defined to classify them as right or wrong. A mean knowledge score was calculated from the knowledge questionnaire by adding up correct answers. Thus, 19

Table 1 The Control Preferences Statement Set (Degner *et al.*, 1997)

Active roles

- A. I prefer to make the decision about which treatment I will receive. (Pure autonomy)
- B. I prefer to make the final decision about my treatment after seriously considering my doctor's opinion. (Informed choice)
- C. I prefer that my doctor and I share responsibility for deciding which treatment is best for me. (Shared decision making)

Passive roles

- D. I prefer that my doctor makes the final decision about which treatment will be used, but seriously considers my opinion. (Professional-as-agent)
- E. I prefer to leave all decisions regarding treatment to my doctor. (Paternalistic)

was the maximum score. Missing answers were classified as wrong. A quadrosplit was used to compare patient groups of different MSK levels and different disease duration. MSK levels and years of disease duration were listed with rising numbers and were then split in four parts of equal size. Item difficulty and item correlation were analysed to describe psychometric properties. The ranking of ten issues of interest out of 30 was coded with '0' up to '10' and calculated as average ranking positions. Role preference ranking sequences were checked concerning construct-validity by checking model fit. Theoretically, only 16 of 120 possible sequences can be regarded as suited to the autonomy continuum.^{19,20} For 145 out of 169 valid replies the model continuum represented the best fitting order to explain the answering profile. The suitable sequences were categorised into five preference categories according to the theoretical differentiated interaction styles, using the first priority as criterion.

Group comparisons were calculated with ANOVA. According to our primary aim to show risk knowledge and information interest differences among different patient groups only correlational analyses were performed between possible factors determining role preferences. Pearson and Spearman correlation coefficients were analysed. Rank scores were calculated for information interests. Results are presented as means \pm standard deviation.

Results

Demographic data (Table 2)

Focus group patients did not differ from survey patients in general demographic characteristics. The response rate of the survey was 79% (169 out of 213): 75 patients with RR and 75 with PP disease. In addition we included 19 patients with a disease course of less than one year. Non-responders of the survey ($n=44$) had longer disease duration but no other demographic factors differing from the studied patients. Six patients did not respond because they felt too ill, 27 declined to participate without giving any specific reason and from 11 patients we received no reply. For further demographic data see Table 1.

Table 2 Demographic data

	Survey ($n = 169$)	Non-responder ($n = 44$)
Female/male (n)	106/63	25/19
Age (years, SD)	44 \pm 11	50 \pm 12
RR-MS (n)	75	21
PP-MS (n)	75	23
Early disease (n)	19	0
Disease duration (years, SD)	7.7 \pm 6.9	12.4 \pm 8.7
Higher education# (n)	69	n.d.
MS immune therapy (n)	103	n.d.

12 or more years of school, n.d. = not determined.
Results as mean \pm SD.

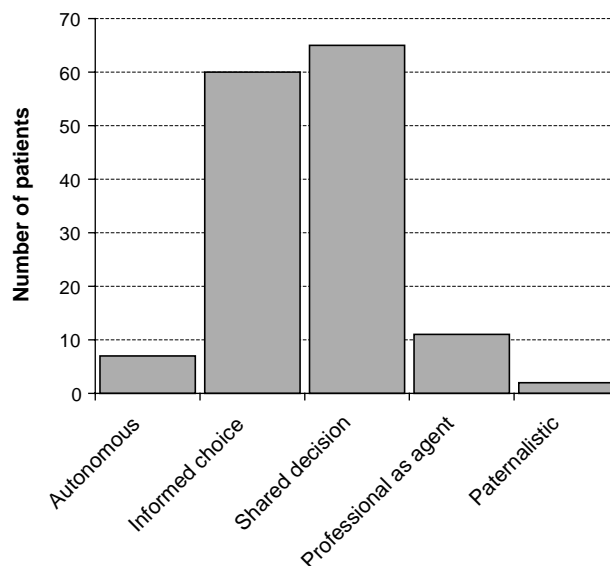


Figure 1 Autonomy preferences among 168 patients with MS. Indicated is the first choice decision making style. Highest priorities were shared decision and informed choice.

Decisional role preferences (Figure 1)

Data on decisional role preferences are given in Figure 1. Most patients ranked the shared decision and the informed choice style highest ($n=65$ and $n=60$, respectively). Taken together 79% (132 out of 168) of patients preferred active roles (i.e., autonomous, informed choice or shared decision) in medical decision making. Despite significant different MSK scores in patient groups with different role preferences (ANOVA $F(4; 140) = 2.9$, $P = 0.024$, see Figure 2) the correlation between knowledge and autonomy was weak (Pearson $r=0.15$). By post hoc grouping of patients according to disease duration

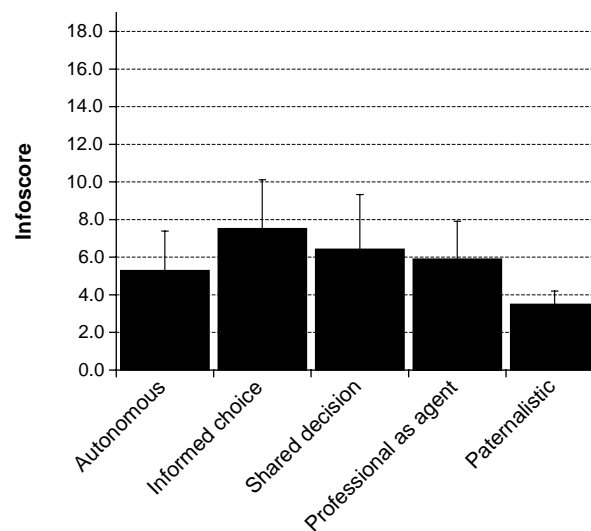


Figure 2 Autonomy preference and knowledge scores among 168 patients with MS. Indicated is the mean knowledge score of each subgroup (\pm SD). Highest scores were among patients preferring informed choice and shared decision. MSK range 0–19, meaning that up to 19 items could be answered correctly.

Role preferences and knowledge in MS

C Heesen *et al.*

4

(quadrosplit), the strongest correlation (Pearson $r=0.4$, $P=0.05$) of MSK and role preferences was found in the patient group with the shortest disease duration (with 0–2 years, $n=42$). As a possible explaining factor knowledge scores were highest among patients with short disease duration. This might be explained by the fact that knowledge may be acquired through the passage of time incidentally. In earlier stages knowledge on the contrary might be more connected to a decision-making process.

Different levels of subjective perceived knowledge (PLK) were also significantly correlated to different role preferences, again supporting the link between autonomy and knowledge (ANOVA $F(4; 135)=3.1$, $P=0.018$). But again the correlation was weak (Pearson $r=0.12$). There were no differences in role preferences when comparing different disease courses and different groups according to the time since diagnosis.

MSK and PLK (Figure 2)

The 19-item knowledge instrument showed satisfactory psychometric properties: difficulty of 13 items was in the range between 0.30 and 0.70. The total item correlation was low (<0.3) for most of the items, indicating that there was not one underlying latent variable explaining the answering pattern. The survey confirmed the focus group findings of the MSK questionnaire. The mean knowledge score was 6.4 (SD 2.4) representing 34% of possible correct answers. One hundred and fifty eight out of 169 patients completed the PLK. Participants rated their subjectively PLK as 63% (where 100% represented maximal knowledge). Both scores, MSK and PLK, differed quantitatively and were only weakly intercorrelated (Pearson $r=0.18$).

MSK scores were associated with the actual relevance of such knowledge for a single patient. This was reflected by significant interactions with indicator variables. Firstly, the highest MSK score was seen in patients with a recent (max. 1 year) MS diagnosis, followed by RR and PP patients (mean score 8.2 ± 3.0 , 7.2 ± 2.6 and 5.2 ± 2.6 , ANOVA $F(2; 166)=15.9$, $P=0.001$). Thus, 38% of the questions in the RR subgroup were answered correctly compared to 27% in the PP group. Secondly, patients on interferon therapies differed in their ability to calculate therapeutic effects of their therapies from patients without

these therapies (mean score 7.3 ± 2.7 versus 6.1 ± 2.8 , ANOVA $F(1; 167)=9.5$, $P=0.002$). Thirdly, by comparing four groups of patients categorised according to their disease duration, recently diagnosed patients had the highest MSK scores (diagnosed within the past 2 years ($n=41$): 7.6 ± 3.1 , diagnosed more than 11 years ago ($n=45$): 4.9 ± 2.3 , ANOVA $F(3; 163)=7.1$, $P=0.000$). In addition, age was negatively correlated with knowledge (Pearson $r=-0.46$; $P<0.000$).

Information interests (Table 3)

According to the questionnaire, patients' interests are to be interpreted as weights of importance not as knowledge requirements. Major information interests were related to alleviation of symptoms (treatment gait disorder, physiotherapy) and magnetic resonance imaging (MRI), followed by knowledge about relapses, including knowledge about steroids, and Eastern complementary medicine (see Table 3). By comparing different disease courses we saw considerable differences. MRI was a prominent interest in recently diagnosed and RR patients. Knowledge about relapses, and Eastern complementary medicine were the first and third choices of RR patients. PP patients showed a strong interest in the treatment of gait disturbances and physiotherapy, followed by experimental therapies. Immunomodulatory therapies were among the lower half of the chosen areas in the whole cohort as well as in the subgroups. Patients with knowledge scores in the upper quartile rated the knowledge item 'validity of studies' among the first three. In the three other patient groups this item was not mentioned among the first ten.

Discussion

This survey is to our knowledge the first to study the correlation of decisional role preferences with subjective and objective knowledge and information interests in a chronic neurological disease.

Decisional role preferences

Most MS patients voted for active roles in medical decision making. In contrast to dichotomous approaches

Table 3 Ranking of information areas according to their relevance to patients

Area	Sample* (n = 169)	Rank (SD) ^o	First year MS* (n = 19)	RR-MS* (n = 75)	PP-MS* (n = 75)
1 Treatment of gait problems	85	2.9 (2.1)	9	28	48
2 Magnet resonance imaging and diagnosis/prognosis	79	5.1 (2.8)	16	37	26
3 Physiotherapy	78	6.1 (2.7)	8	29	41
4 Relapses and prognosis/disease course	75	5.1 (2.9)	14	48	13
5 Eastern complementary medicine	71	6.6 (2.4)	6	37	28
6 Steroid treatment	69	5.7 (2.7)	10	36	23
7 Experimental therapies	64	4.9 (3.2)	7	30	30
8 Fatigue treatment	56	5.1 (2.5)	8	26	22
9 Interferons	55	5.6 (3.0)	6	29	20
10 Knowledge on study evidence	55	6.3 (3.0)	8	23	24

* Number of patients who chose the item at any position among ten preselected items.

^o Mean rank among those patients who chose the item, maximum 1, minimum 10.

(active versus passive role choice) ordering of roles as in the control preference scale may lead to more robust estimates of patient preferences. Other ways of evaluating control preferences have shown to seriously overestimate the percentage of people who want to participate in decision making.²¹ Studies have shown that compared to scenarios involving potential mortality, patients prefer more involvement in scenarios with chronic conditions or quality of life issues.²² So the specific question involved has a major impact. As MS is a chronic condition our findings are in line with this study.

Hypothetical role preferences might not anticipate patients' behaviour in real life decisions as Entwistle *et al.*²³ have shown in hysterectomy decision-making processes. Nevertheless, control preferences reflect a sense of control if the desired role is active. This may yield positive effects on disease outcome, if only on psychological factors, regardless whether this hypothetical preference may lead to a real autonomous decision or not.^{24,25} Degner²⁶ compared desired and actual roles by comparing patient ratings before and after a decision has been made in breast cancer treatment. Only 42% of women believed they had achieved their preferred level of control in decision making. Thus, our results are relevant but might not be a strong predictor for real participation.

MS risk knowledge

Overall, risk knowledge was low in our survey. We especially asked for risk calculation abilities requiring filling in percentages. This is not the usual way patients are informed for example by brochures from pharmaceutical companies. Is the knowledge of absolute risks necessary for decision processes from the patient perspective? It has been repeatedly shown that this kind of information increases the proportion of patients who have a realistic perception of benefits and risks.²⁷ Agreement between chosen treatment and patient values could be increased by giving patients percentage estimates of risk, leading to an improved treatment adherence. We therefore think that information about risks and uncertainties which includes communicating numbers should be made available for patients. On the other hand patients might have been much better informed about disability issues which we did not ask for. This corresponds to the findings in the information interest questionnaire giving symptom alleviation a high priority. The fact that MS frequently leads to cognitive deficits may also account for lower knowledge scores with longer disease duration.

According to our hypothesis knowledge should depend on disease factors such as disease course, disease duration and ongoing therapy. Thus, it seems plausible that knowledge of MS therapies should be less in PP, as there is no proven therapy for this group of patients. Recently diagnosed patients had highest knowledge scores and knowledge did not increase with age or disease duration in our sample. We conclude that risk knowledge levels depend on the actual relevance of this knowledge, which is higher in early disease stages where more therapies are available.

Perceived level of knowledge

Subjective knowledge was only weakly correlated to the knowledge evaluated by the questionnaire. Patients' role preferences in decision processes may be mediated by important factors apart from MSK. Patient assessment of subjective knowledge in our study may point to those additional factors, as it may partly reflect personality factors such as self-efficacy. As a limitation our study did not study personality and psychological factors in more detail. The study supports the assumption that personal attitudes and beliefs have a large impact on role preferences in decision processes. But, as subjective knowledge was assessed with a visual analogue scale compared to a 19-item questionnaire for MS knowledge, the weak correlation with the MSK should be considered with caution. Prosser *et al.*²⁸ have shown that therapy initiation among MS patients depends on risk attitudes as assessed by a standard gamble question. Risk-seeking patients were less likely to choose treatments compared to risk-averse patients supporting the suggestion that personal factors have a large impact on decisional processes.

Correlation of decisional role preferences and knowledge

Higher knowledge scores were only weakly correlated to preferences for more active roles. Thus, we can not conclude a strong relationship between these factors. Knowledge might lead to a preference for active roles. On the other hand, patients preferring autonomous roles may take more active steps to discover information. However, since the association between the MSK and active roles is weak, its contribution to autonomy is limited. This corresponds to a systematic review of informed decision-making interventions of Bekker *et al.*,²⁹ who recommended measures of reasoning, affect and information processing as possibly important factors influencing the effect of an intervention with an information tool. The same has recently been shown by O'Connor *et al.*³⁰ The authors demonstrated that, apart from knowledge, unclear personal values, social pressure, readiness and decision-making skills were major factors contributing to decisional conflict in health decisions among 635 Canadians, randomly interviewed by telephone. Thus, a well-balanced evidence-based information tool is clearly only one factor enabling patient participation in health care.

Information interests

Information interests were largely influenced by disease stage and disease course, but treatment of gait disorder was the most frequently mentioned item. Symptom alleviation is easy to judge in its efficacy and obvious in its intent to increase quality of life. On the other hand, immune therapies might negatively influence current quality of life in relation to an uncertain goal to be achieved in the future. It seems plausible that people affected by a chronic disease turn to therapeutic concepts that promise reduction of uncertainty and alleviation in coping with everyday life. Our results are supported by another study also reporting symptom alleviation as the major unmet information need.¹³ Thus, we suspect that in

the areas rated most important, there is nearly always an unmet information need. This may indicate patients' hope and need for information about an effective treatment option.

There was a strong interest in MRI knowledge in early MS disease phases, as MRI is increasingly considered the most adequate method of diagnosing MS and of giving some estimate concerning prognosis. The lower rating of immune therapies may point to the critical appraisal of these. Another explanation might have been the fact that patients think they already know enough about these which is to some extent contrary to our MSK results.

Information seeking could be looked at as a coping style. This might explain the fact that information deficits and unmet information needs have been repeatedly acknowledged in MS^{13,31} despite a large array of information sources such as the Internet. There are situations when it might even be more helpful to distract oneself from and psychologically blunt threatening cues thereby blocking information uptake.³² This again stresses the fact that information is just one factor enabling patient participation in decision making.

A limitation of our study is a 20% non-responder rate. But as different patient groups with high patient numbers were randomly selected we do not think that our results are biased by these dropouts. Furthermore demographic data of the non-responder group did not indicate that these form a special subgroup. The non-randomly included 19 patients with early disease did not influence the overall main results (data not shown). So we do not think that they biased our findings.

In conclusion patients with MS claimed they wanted active roles in their health care decisions. This role preference correlated only weakly to patients' knowledge about MS and related medication. Risk information is essential to enable autonomous decisions, but other factors are also important. We speculate that these results are also attributable to other chronic neurological conditions. To clarify to what extent such role preferences predict decisions in real life and to weight the impact of scientific risk information on patient role preferences and autonomy, controlled trials are needed.

Acknowledgement

This study was funded by a grant from the German Ministry of Health: 'Informed shared decision-making in the therapy of multiple sclerosis' Grant No. GMQ01019401.

References

- 1 General Medical Council: Protecting patients, guiding doctors. Seeking patients' consent: the ethical considerations. London W1N 6JE, 1999 (<http://www.gmc-uk.org>). Last accessed 2 September 2004.
- 2 Coulter A, Entwistle V, Gilbert D. Sharing decisions with patients: is the information good enough? *Br Med J* 1999; **318**: 318–22.

- 3 Tremlett HL, Luscombe DK, Wiles CM. Use of corticosteroids in multiple sclerosis by consultant neurologists in the united kingdom. *J Neurol Neurosurg Psych* 1998; **65**: 362–65.
- 4 Filippini G, Munari L, Incorvaia B, Ebers GC, Polman C, D'Amico R *et al.* Interferons in multiple sclerosis. a systematic review. *Lancet* 2003; **61**: 45–52.
- 5 Köpke S, Heesen C, Kasper J, Mühlhauser I. Steroid treatment for relapses in multiple sclerosis – the evidence urges shared decision making. *Acta Neurol Scand* 2004; **110**: 1–5.
- 6 Charles C, Gafni A, Whelan T. Decision-making in the physician–patient encounter: revisiting the shared treatment decision-making model. *Soc Sci Med* 1999; **49**: 651–61.
- 7 National Institute for Clinical Excellence: Multiple sclerosis. Management of multiple sclerosis in primary and secondary care. Clinical Guideline 8, November 8, 2003, available at the NICE Website: <http://www.nice.org.uk>
- 8 Edwards A, Elwyn G, Mulley AL. Explaining risks: turning numerical data into meaningful pictures. *Br Med J* 2002; **324**: 827–30.
- 9 O'Connor A, Rostom A, Fiset V, Tetroe J, Entwistle V, Llewellyn-Thomas H *et al.* Decision aids for patients facing health treatment or screening decisions: systematic review. *Br Med J* 1999; **319**: 731–34.
- 10 Rothwell PM, McDowell D, Wong CK, Dorman PJ. Doctors and patients do not agree: cross sectional study of patients' and doctors' perceptions and assessments of disability in multiple sclerosis. *Br Med J* 1997; **314**: 1580–83.
- 11 Freeman JA, Thompson AJ. Community services in multiple sclerosis: still a matter of chance. *J Neurol Neurosurg Psych* 2000; **69**: 728–32.
- 12 Wollin J, Dale H, Spenser N, Walsh A. What people with newly diagnosed MS (and their families and friends) need to know. *Int J MS Care* 2000; **2**: 4–14.
- 13 Vickrey BG, Shatin D, Wolf SM, Shapiro MF, Delrahim S, Belin TR *et al.* Management of multiple sclerosis across managed care and fee-for-service systems. *Neurology* 2000; **55**: 1341–49.
- 14 Heesen C, Kolbeck J, Gold SM, Schulz H, Schulz KH. Delivering the diagnosis of MS – results of a survey among patients and neurologists. *Acta Neurol Scand* 2003; **107**: 363–68.
- 15 Mushlin DH, Mooney C, Grow V, Phelps CE affiliated with the Rochester–Toronto MRI Study Group. The value of diagnostic information to patients with suspected multiple sclerosis. *Arch Neurol* 1994; **51**: 67–72.
- 16 O'Connor P, Detsky ASA, Tansey C, Kucharczyk W and the Rochester–Toronto MRI-Study group. Effect of diagnostic testing for multiple sclerosis on patient health perceptions. *Arch Neurol* 1994; **51**: 46–51.
- 17 Mohr DC, Goodkin DE, Likosky W, Gatto N, Neilley LK, Griffin C *et al.* Therapeutic expectations of patients with multiple sclerosis upon initiating interferon-beta 1-b: relationship to adherence to treatment. *Mult Scler* 1996; **5**: 222–26.
- 18 Heesen C, Kasper J, Busche J, Koepke S, Mönch A, Mühlhauser I. Risk communication in multiple sclerosis: information needs, autonomy preferences and effects of an evidence-based information. The 2nd International Shared Decision Making Conference 2–4 September 2003, Swansea, University of Wales.
- 19 Degner LF, Sloan JA, Venkatesh P. The control preference scale. *Can J Nurs Res* 1997; **29**: 21–43.
- 20 Zysno PV. Ordinale Entfaltung. In Zysno PV ed. *Qualitative Verbundmessung*. Lengerich, Berlin, Düsseldorf, Leipzig, Riga, Scottsdale, Wien, Zagreb: Papst Sciences Publishers, 1999: 83–111.

Role preferences and knowledge in MSC Heesen *et al.*

7

- 21 Blanchard CG, Labrecque MS, Ruckdeschel JC, Blanchard EB. Information and decision-making preferences of hospitalized cancer patients. *Soc Sci Med* 1980; **7**: 1139.
- 22 Deber RB, Kraetschmer N, Irvine J. What role do patients wish to play in treatment decision making? *Arch Int Med* 1996; **156**: 1414.
- 23 Entwistle VA, Skea ZC, O'Donnell MT. Decisions about treatment: interpretations of two measures of control by women having a hysterectomy. *Soc Sci Med* 2001; **53**: 721–32.
- 24 Morris J, Royle GT. Offering patients a choice of surgery for early breast cancer: a reduction in anxiety and depression in patients and their husbands. *Soc Sci Med* 1988; **26**: 583.
- 25 Fallowfield, Hall A, Maguire GP, Baum M. Psychosocial outcomes of different treatment policies in women with early stage breast cancer outside a clinical trial. *Br Med J* 1990; **301**: 575.
- 26 Degner LF, Kristjanson L, Bowman D, Sloan JA, Carriere KC, O'Neil J *et al.* Decisional preferences and information needs in women with breast cancer. *J Am Med Assoc* 1997; **277**: 1485.
- 27 O'Connor AM, Légaré F, Stacey D. Risk communication in practice: the contribution of decision aids. *Br Med J* 2003; **327**: 736–40.
- 28 Prosser LA, Kuntz KM, Bar-OR A, Weinstein MC. The relationship between risk attitude and treatment choice in patients with relapsing-remitting multiple sclerosis. *Med Decis Making* 2002; **22**: 506–13.
- 29 Bekker H, Lilleyman J, Thornton JG, Connolly JB, Hewison J, Robinson MB *et al.* Informed decision making: an annotated bibliography and systematic review. *Health Technol Assess* 1999; **3**: 1–158.
- 30 O'Connor AM, Drake ER, Wells GA, Tugwell P, Laupacis A, Elmslie. A survey of the decision making needs of Canadians faced with complex health decisions. *Health Expect* 2003; **6**: 97–109.
- 31 Sommerset M, Campbell R, Sharp DJ, Peters TJ. What do people with MS want and expect from health-care services? *Health Expect* 2001; **4**: 29–37.
- 32 Baker LM. A new method for studying patient information needs and information seeking patterns. *Top Health Inform Manage* 1995; **16**: 19–28.

Appendix A questionnaire MSK

(Several answers could be correct, ● = the correct answers(s), in some questions several combinations have been considered correct)

How would you in general rate your knowledge about MS? (visual analogue scale)

Being not informed at all _____
Being very well informed

1. What are relapses?

- New symptoms which develop within days or weeks)
 - Old symptoms, which reappear just for some hours
 - Worsening of old symptoms or new symptoms which appear and remain for at least 24 hours
 - Worsening of symptoms which sometimes are difficult to differentiate from daily fluctuations
- (3 and any other excluding the 2nd answer also weighted as correct)

2. When could a diagnosis of MS be made?

- After the first symptoms
- Only when certain symptoms are given
- After the first symptoms appeared with additional tests
- From the disease course
- Possibly never for certain

(3 and any other than the first and 2nd also weighted as correct)

3. The disease course of MS has been studied amongst people attending different MS centres. From these studies prognostic factors have been delineated. Based

on these studies what is the level of impairment after 15 years of MS?

- About 30% able to walk without help
 - About 50% of patients able to walk without help
 - About 70% of patients able to walk without help
 - I do not know
- (only the 2nd correct)

4. Are these results applicable to the whole group of MS patients in one geographical region?

- Yes
 - No
 - I do not know
- (only 2 correct)

5. Which factors do correlate with the rate of progression and the level of impairment in the long-term in MS, i.e., the prognosis?

- Gender
 - Disease course
 - Kind of first symptoms
 - Relapse rate in the first years
 - Age
 - A minor impairment during the first 5 years
 - Severity of the first symptoms
 - Number of lesions on the first MRI
- (at least 3 should be correct)

6. Which MS therapies have been approved by the German health institutions?

- Interferons
- Copaxone
- Methotrexate
- Azathioprine
- Mitoxantrone

Role preferences and knowledge in MS

C Heesen *et al.*

8

- Immunoglobulines
○ I do not know
(all should be correct)
7. Disability without therapy
Imagine you have a relapsing-remitting disease course. You have two relapses per year. In....% (out of 100) patients there is no worsening of impairments **without** treatment during 2 years of follow-up. (Please fill in)
(Correct would be 65–85%)
8. Disability on treatment
Imagine you have a relapsing-remitting disease course. You have two relapses per year. A recently initiated interferon treatment should slow down the worsening of impairments. In....% (out of 100) patients there is no worsening of impairments **with** treatment during 2 years of follow-up. (Please fill in)
(Correct would be 70–90%)
9. Asked differently
In question 7 you calculated the patients remaining stable without therapy. How many patients additionally remain stable due to an interferon treatment? Answer: Out of 100 patients....% additionally remain stable during 2 years of follow-up
(Correct would be 10–30%)
10. What is the effect of copaxone on relapse rates?
● Similar to interferons
○ Less than interferons
○ More than interferons
○ I do not know
(the first answer would be correct)
11. In the following you will find statements on the comparison of interferons and azathioprine. Which are correct?
○ Interferons are more effective
● Some studies have shown an increased cancer risk on azathioprine treatment
○ Side effects of interferons are much more tolerable than those of azathioprine
● As no direct comparative trials exist it is not possible to answer which drug is more effective
○ I do not know
(4 alone would be correct)
12. Studies on the effect of interferons in secondary MS have shown
○ No stabilizing effect on the disease course
○ A stabilizing effect on the course
● A minor stabilizing effect on the disease course
● Contradictory results
(3 alone would be correct)
13. If 100 patients start an interferon treatment, ... would have flu-like symptoms in the beginning? (Please fill in)
(60–80% would be correct)
14. If 100 patients with secondary-progressive MS start mitoxantrone treatment, how many patients will have a benefit during 2 years therapy?
● 10
● 20
○ 30
○ 40
○ More than 40
○ I do not know
(1 or 2 alone would be also correct)
15. What is the effect of the above mentioned ms therapies in general?
○ Healing the disease
○ Stopping the progress
● Slowing the progress
● Fewer relapses
(3 or 4 would be also correct)
16. Which disease course of MS is still without any convincing therapeutic study?
○ First bouts, so called isolated clinical symptoms
○ Secondary progressive MS
● Primary progressive MS
(3 would be correct)
17. If you experience a relapse, what effect do you expect from a steroid treatment?
● Shortening of the relapse-time
○ Fewer remaining symptoms than without treatment
○ A slowing of the disease progress
(the first answer would be correct)
18. What is a double-blind placebo-controlled trial?
○ A study in which new drug is compared with an old one
● A study in which a drug (Verum) is compared to a fake-drug (placebo). Physician and patient do not know who receives which. Patients will be given one of the drugs randomly.
○ A trial in which a drug is studied in comparison to a placebo. Patients will be randomly put on these drugs. But physicians know who is treated with which drug.
○ A trial in which patients are blindfolded twice and who then try different medications.
○ I do not know
(2 would be correct)
19. A double-blind placebo controlled trial
● Gives the best information about the effectiveness of a drug
○ Always proves if a drug is beneficial or not
● Often only gives effectiveness data for a selected group of patients
○ I do not know
(1 alone would be correct)