

Patient information on cognitive symptoms in multiple sclerosis – acceptability in relation to disease duration

Heesen C, Segal J, Reich C, Hämäläinen P, Broemel F, Niemann S, Simon U, Gross R, Kasper J. Patient information on cognitive symptoms in multiple sclerosis – acceptability in relation to disease duration.

Acta Neurol Scand 2006; 114: 268–272.
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Objective – Recently, regular cognitive screening assessments have been advised in multiple sclerosis (MS). No studies have been carried out yet on the acceptability of information on cognitive deficits among MS patients. **Materials and methods** – Translation of an information booklet developed by a working group of European MS Rehabilitation Centers. Distribution of the booklet among 133 MS patients of two rehabilitation units and one outpatient clinic together with a one-page questionnaire. **Results** – The booklet was highly understandable and rated to give moderate new information. Overall, the brochure was perceived as encouraging but significantly less so ($P = 0.014$) in recently diagnosed patients. Patients with subjectively perceived deficits considered the brochure to be significantly more relevant ($P = 0.002$). **Conclusion** – Information on cognitive deficits does not increase fears even in recently diagnosed MS patients. Patients with perceived deficits found the information more relevant than others and also less familiar. Thus, it seems appropriate to offer information about cognitive impairments to MS patients.

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Key words: cognitive dysfunction; multiple sclerosis; patient information

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Accepted for publication February 1, 2006

The relevance of cognitive dysfunction in multiple sclerosis (MS) has been underestimated until recent years (1). Nevertheless, the prevalence of cognitive dysfunction is 45–65% depending on the sensitivity of neuropsychological tests (2). In most cases, deficits are mild but may have significant impact on patients' life. Furthermore, cognitive dysfunction and fatigue are said to be major reasons for early retirements and unemployment – even more so than walking difficulties (3). Finally, patients rate mental and emotional health higher than physical disability and higher than their physicians, again underlining the relevance of cognitive symptoms (4).

Cognitive function is assumed to be the best correlate of overall brain damage in MS which is underlined by strong correlations with overall lesion

load and atrophy on magnetic resonance imaging (5). Early neuropsychological deficits have been described in MS (3, 6) and several studies now address their prognostic relevance. Increasingly patients are confronted early on in the course of their disease with neuropsychological tests. On the other hand, testing of cognitive function in MS is time-consuming and may confront patients with deficits of which they were not previously fully aware. In addition, cognitive symptoms are not always obvious to others nor easily distinguishable from personality factors. Professionals may be wary of unnecessarily frightening patients who will never develop cognitive deficits or may be unaware of the role of cognitive deficits in MS. Therefore, cognitive symptoms in MS may not be discussed with a patient by a professional who understands them.

Considering the relevance of cognitive function in general, but also the above-mentioned difficulties of confronting patients with an early assessment, a major question is how patients perceive information on cognitive problems in MS. In the early stages of the disease many patients experience no neurologic complaints between relapses and most of them try to live a normal life; information about cognitive deficits given at this time might be more disturbing than helpful.

On the other hand, patient information is increasingly recognized as a prerequisite for patient participation in health care (7). The MS management guidelines for UK (8) thus demand an educational program covering all aspects of MS within 6 months of diagnosis. We have recently shown that MS patients want autonomous roles in their health management, and that information plays a key role (9).

This study aimed to investigate the effect of a patient information brochure on cognitive dysfunction in MS. Our hypothesis was that well-balanced, reassuring information on cognitive dysfunction will give new and important information to MS patients and will not increase anxiety even if presented in early stages of the disease.

Materials and methods

Construction of the patient information

The patient information was developed by the ‘Psychology and Neuropsychology Clinical Care Committee’ of the European organization for rehabilitation in MS (RIMS) authored by P. Hämäläinen, S. Rigby, J. Segal, A. Jönsson, P.Thomson, M. Pirard, and R. Vermote. The information was published by the British MS Society in 2002 and then translated into German in 2003 with the help of a professional translator.

The 14-page brochure including five citations from medical papers covers nine aspects (see Table 1).

Survey sample

The brochure was distributed to consecutive patients via the MS Outpatient Clinic of the University Medical Center Hambrug-Eppendorf, Hamburg and via the neuropsychological departments of the Outpatient Rehabilitation Unit Berliner Tor in Hamburg and the Inpatient Rehabilitation Unit in Bad Segeberg. They were informed that the booklet was a translation of a brochure developed by European MS Rehabilitation Centers (RIMS) dealing with cognitive symp-

Table 1 Structure of the brochure

What is cognition?
Does MS affect memory and thinking? (With reference to other factors than cognitive decline which affect memory and thinking)
Am I the only one?
What kinds of problems might there be?
Can cognitive problems be predicted?
What should I do if I suspect cognitive problems?
Self-help or professional help?
What is neuropsychological rehabilitation?
Hints for coping and further tips
Talking about complaints and feelings and the development of compensation strategies are stressed

toms in MS. Together with the booklet all patients received a one-page questionnaire and a return envelope and were asked to reply within 4 weeks.

Questionnaire

The questionnaire included MS demographic questions on gender, age and disease duration. Patients were asked if they had experienced any problems with attention, memory or thinking. Out of a larger pool of items about perception and acceptability we selected five dimensions as relevant for the emotional appraisal of the information: extent of familiarity, understanding, relevance, interest, and encouragement. The resulting pairs of adjectives characterizing the extreme poles of the induced feeling were: ‘unfamiliar’ vs ‘already familiar with the information’ (familiarity item), ‘complete understanding’ vs ‘no understanding’ (understanding item), ‘high relevance’ vs ‘low relevance’ (relevance item), ‘evokes my interest’ vs ‘did not evoke my interest’ (interest item) and ‘evokes fears’ vs ‘encouraged me’ (encouragement item). Patients had to mark a point on a visual analog scale (VAS) that corresponded to their feeling with ‘0’ indicating a neutral feeling, +5 and –5 representing the extreme values. This answer format is suitable to inhibit cognitive answering control and to allow maximal variance (10). The items had been successfully pretested in a previous study on the perception of evidence-based patient information in MS (11). As a result, feasibility of the answer format, sufficient variance and face validity could be assumed at the beginning of the study. Furthermore, reliability was checked with the thinking-aloud methodology asking patients to phrase their answers in the presence of a research assistant. All five interviews underlined the reliability of the questionnaire results.

Finally, patients were asked if they would have preferred to read the information earlier (3 = yes, 2 = do not know, 1 = probably no) and if they

could recommend the brochure to all MS patients (4 = definitely yes, 3 = yes, 2 = do not know, 1 = probably no).

Statistical analysis

Descriptive data are presented by median values and interquartile ranges (IQR: 25th–75th percentile). Between-group comparisons were made using Mann–Whitney *U*-tests. All calculations were performed with SPSS 11.0 for Windows. Subgroup analyses were performed on the ‘very early MS’ group (<2.5 years) as the information could have more disturbing effects on newly diagnosed people who may be both unaffected themselves and unaware that cognitive deficits are potential MS symptoms. Patients with perceived cognitive deficits were also separately analyzed.

Results

Demographic data

One hundred thirty three questionnaires were returned. Data from 128 patients were analyzed. They were 91 women and 37 men with a median age of 41 (IQR 34–48) years. Median disease duration was 8.0 (IQR 3–14.3) years. Ninety four patients (73%) reported that they had recognized some difficulties in concentration, memory or thinking. Thirty four (27%) reported these as main complaints.

Perception of the information in general

On the ‘familiarity’ scale, there was a large range of responses, with as many finding the information new as found it familiar, resulting in a nearly neutral median score (0.75) but a large IQR of –1.5 to 3.2 (see Fig. 1). On the other hand, nearly everyone found the information highly ‘understandable’; the median score was 4.6 and the IQR only 4.2–4.8. Respondents rated the brochure as quite ‘relevant’ with a median score of 3.05 (IQR 1.3–4.6). To a lesser extent, interest was induced (median score 2.2, IQR –0.3 to 4.2) and to the same extent patients felt encouraged (median score 2.2, IQR 0–3.9).

Perception in early MS

In the subgroup of patients who were diagnosed <2.5 years ago (*n* = 20, median age 35 years; IQR 28.5–45), 10 (48%) reported as perceiving cognitive deficits. As can be seen in Table 2, their answering patterns were quite similar to the whole cohort.

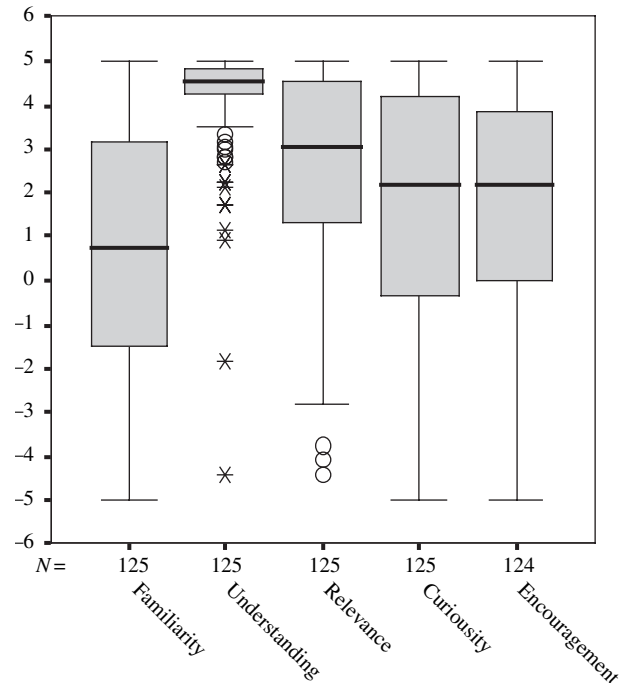


Figure 1. Answering patterns of the whole sample. Responses to the questions: familiarity, understanding, relevance, curiosity, and encouragement in box and whisker plots. O, outliers (values whose distance from the 75th percentile is 1.5 to 3 times the distance between the 25th and the 75th percentile). *Extreme values (values whose distance from the 75th percentile is more than three times the distance between the 25th and the 75th percentile).

However, these patients were significantly less encouraged than in the rest of the cohort (median score of 0.5 vs 2.7, Mann–Whitney *P* = 0.014). Newly diagnosed patients reported the information as being more new for them than the rest of the cohort, although this was not significant (median score 2.7 vs 0.7). Answering patterns of patients with disease courses longer than 2.5 and <10 years did not differ from the whole cohort.

Perception among patients with perceived cognitive deficit

Ninety four patients reported a perceived cognitive deficit (median age 43, IQR 34–49.5; median disease duration 8.0, IQR 3.7–15) (see Table 2). Not surprisingly, they found the information more relevant (*P* = 0.001) than those who did not report a cognitive deficit. A substantial number of these patients with perceived deficits found the information new (median score 0.7, IQR –0.15 to 3). Their understanding did not differ from that of patients who did not perceive any deficit (*P* = 0.44). Furthermore, there was a trend for this group being more encouraged (*P* = 0.058) and getting more interested in the topic (*P* = 0.058) compared to patients without perceived cognitive deficit.

Table 2 Answering patterns according to subgroups

	Early MS	Rest of the cohort	Perceived cognitive deficit	Rest of the cohort	Early MS and perceived cognitive deficit	Rest of the cohort
<i>n</i>	20	103	91	34	10	113
Familiarity	2.7 (-1.4/3.8)	0.7 (-1.8/2.7)	0.7 (-1.5/3)	0.9 (-1.5/4.0)	2.8 (-1.1/3.5)	0.7 (-1.8/3.1)
Understanding	2.7 (4.5/4.8)	4.6 (4.2/4.8)	4.6 (4/4.8)	4.7 (4.4/4.8)	4.7 (4.1/4.8)	4.6 (4.2/4.8)
Relevance	3.3 (0.3/4.6)	3.2 (1.4/4.7)	3.9 (1.7/4.7)*	0.9 (-1.5/4.1)	4.5 (2.1/4.8)	3.1 (1.3/4.6)
Curiosity	2.0 (-1/3.7)	2.4 (-0.2/4.4)	2.6 (0.1/4.4)	0.4 (-1.0/3.3)	3.2 (-0.2/4.2)	2.2 (-0.3/4.3)
Encouragement	0.5 (-2.3/2.2)*	2.7 (0.3/4.0)	2.5 (0.2/4)	0.6 (-0.7/3.3)	0.7 (-2.4/2.6)	2.3 (0.2/4.0)

Results are median (25th/75th percentile). Patients in column 3 represent the intersection of column 1 and column 3.

*Significant difference to the rest of the cohort (Mann–Whitney).

In particular, those patients with early MS (<2.5 years) who had already recognized some deficits (*n* = 10) had answering patterns which differed from the rest of the group: They reported the information about cognitive deficits in MS being more new for them (median score of 2.8 vs 0.7, IQR -1.0 to 3.5 and -1.8 to 3.1); they found the information more relevant (median score of 4.5 vs 3.0, IQR 2–4.8 and 1.3–4.6); and they reported that they were more curious (median score of 3.3 vs 2.2, IQR -0.2 to 4.2 and -0.3 to 4.3). On the other hand, they felt less encouraged (median score of 0.7 vs 2.3, IQR -2.4 to 2.6 and 0.2–4.0). However, these differences were not significant, which might be due to the small number of patients in this subgroup (*n* = 10).

Considering only recently diagnosed patients without perceived deficit the brochure was rated significantly as less encouraging (*P* = 0.048) than by the other patients.

Recommendation for other patients

All respondents recommended the information for all patients (median score 3.0, IQR 3–4) as well as, on average, preferring an earlier presentation (median score 3.0, IQR 2–3). Patients with early MS and without perceived cognitive deficits (*n* = 10) were not sure if they would have liked an earlier presentation (median score 2.0, IQR 2–3, Mann–Whitney *P* = 0.000). Nevertheless, they recommended the brochure for other patients even though they recommended it to a lower extent than the rest of the group (Mann–Whitney *P* = 0.043).

Discussion

Cognitive impairment is a common but usually not the most severe complaint in MS. On the other hand, mental health is a major concern of patients. Increasingly regular cognitive assessment to monitor disease progress is addressed by MS research-

ers and physicians. But little is known about how patients perceive information on cognitive deficits in relation to disease duration and subjective complaints. The information booklet prepared by a neuropsychology–psychology working group of RIMS was highly understandable. As a major finding the booklet did not evoke fears, even in patients with early MS. We thus conclude that information on cognitive deficits can be administered to patients during the first 2 years after diagnosis is made. On the other hand, early MS patients without perceived deficits would not have preferred to have received the information earlier. As an explanation these patients might not consider this topic as relevant, alternatively the information might have been unnecessarily frightening – which is not, however, supported by the data from the VAS ‘encouragement’. The initial period after an MS diagnosis has been made is considered to place the highest burden on patients with regard to developing coping mechanisms to deal with the uncertainty concerning their future individual disease course. Depression and anxieties are common at this stage among patients and their relatives (12). Diagnosis disclosure and further information on the disease should be a stepwise process delivering only the information patients are able to deal with (13). Understandable, evidence-based information should be made easily available. This finding is in line with our recent study on diagnostic disclosure (14) and patient information (9). Even patients with minor disabilities in the follow-up would have liked an earlier diagnostic disclosure in retrospect. As patients with perceived cognitive deficits in the early stages also rated the brochure as more important with a trend toward being more encouraged, screening questions for subjective complaints might be a guideline for information delivery. Furthermore, a substantial number of patients with perceived cognitive deficit rated the information as new which suggests that people who need the information are not currently receiving it. We thus recommend information on cognitive deficits

as well as on other symptoms in MS for every patient complaining about difficulties, regardless of whether they objectively exist.

The limitations of our survey were that we had no random sample and we had no information on non-responders, which was about 10% of the distributed brochures. But demographic data and the analysis of an early MS subgroup seem to justify a generalizability of our findings. We did not check whether patients really read the booklet and to what extent. As we performed no formal neuropsychological assessment, no conclusion is possible on the perception of this information in patients with proven cognitive deficits. As patients with subjectively perceived deficits did report a higher positive acceptance of the brochure, we suspect that patients with objectively proven deficits might also profit from the information tool.

Conclusion

Our study offers further proof that carefully developed patient information is recommended by patients for other patients even when touching such sensitive areas as mental health and confronting patients with possible deficits of which they are not currently aware.

Acknowledgements

The translation of the brochure and printing of the German version was sponsored by Biogen-Idec. We especially thank the Clinical Care Committee Neuropsychology-Psychology of RIMS for the opportunity to translate and evaluate their information booklet.

References

1. BOBHOLZ JA, RAO SM. Cognitive dysfunction in multiple sclerosis: a review of recent developments. *Curr Opin Neurol* 2003;**6**:283–8.
2. RAO SM. Neuropsychology of multiple sclerosis. *Curr Opin Neurol* 1995;**8**:216–20.
3. AMATO MP, PONZIANI G, SIRACUSA G, SORBI S. Cognitive dysfunction in early-onset multiple sclerosis: a reappraisal after 10 years. *Arch Neurol* 2001;**58**:1602–6.
4. ROTHWELL PM, McDOWELL D, WONG CK, DORMAN PJ. Doctors and patients don't agree: cross sectional study of patients' and doctors' perceptions and assessments of disability in multiple sclerosis. *Br Med J* 1997;**314**:1580–3.
5. FISHER E, RUDICK RA, SIMON JH et al. . Eight-year follow-up study of brain atrophy in patients with MS. *Neurology* 2002;**59**:1412–20.
6. ACHIRON A, BARAK Y. Cognitive impairment in probable multiple sclerosis. *J Neurol Neurosurg Psychiatry* 2003;**74**:443–6.
7. COULTER A, ENTWISTLE V, GILBERT D. Sharing decisions with patients: is the information good enough? *Br Med J* 1993;**318**:318–22.
8. NATIONAL INSTITUTE FOR CLINICAL EXCELLENCE. Multiple sclerosis. Management of multiple sclerosis in primary and secondary care. Clinical Guideline 2003 [WWW document]. URL <http://www.nice.org.uk> [accessed on 1 March 2006].
9. HEESEN C, KASPER J, SEGAL J, KOEPKE S, MÜHLHAUSER I. Decisional role preferences, knowledge and information interests in patients with multiple sclerosis. *Mult Scler* 2004;**10**:643–50.
10. MÜLLER H. A Rasch model for continuous ratings. *Psychometrika* 1987;**52**:165–81.
11. KASPER J, KÖPKE S, MÜHLHAUSER I, HEESEN C. Evidence-based patient information about treatment of multiple sclerosis – a phase one study on comprehension and emotional responses. *Pat Ed Counsel* 2005 [Epub ahead of print].
12. JANSSENS AC, VAN DOORN PA, DE BOER JB, VAN DER MECHE FG, PASSCHIER J, HINTZEN RQ. Impact of recently diagnosed multiple sclerosis on quality of life, anxiety, depression and distress of patients and partners. *Acta Neurol Scand* 2003;**108**:389–95.
13. VITALI S. Paraclinical support of the person diagnosed with MS. *Int MS J* 2004;**11**:2–9.
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* 2002;**107**:363–8.