The INTERMED: a screening instrument to identify multiple sclerosis patients in need of multidisciplinary treatment

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Objective: To analyse the value of the INTERMED, a screening instrument to assess case complexity, compared with the Expanded Disability Status Scale (EDSS) and the Guy's Neurological Disability Scale (GNDS) to identify multiple sclerosis (MS) patients in need of multidisciplinary treatment.

Methods: One hundred MS patients underwent INTERMED, EDSS, and GNDS examinations. Patient care needs were assessed by a multidisciplinary team and a goal oriented treatment plan was defined. Correlations between INTERMED, individual INTERMED domains, EDSS, GNDS sum score, and total number of proposed disciplines involved in the treatment plan were studied.

Results: Mean (SD) age was 40.6 (10.1) years. Median scores were 14.0 for the INTERMED, 4.0 for the EDSS, and 13.5 for the GNDS sum score. Moderate correlations were found between the INTERMED sum score and EDSS ($r=0.59$) and GNDS sum score ($r=0.60$). The number of disciplines as proposed by the multidisciplinary team showed the highest statistically significant correlation with the INTERMED sum score ($r=0.41$) compared with EDSS ($r=0.32$) and GNDS sum score ($r=0.34$). No significant or only weak correlations were found between the psychological domain of the INTERMED and EDSS or GNDS.

Conclusion: The findings in this study show that there is an additional value of the INTERMED compared with the EDSS and GNDS in identifying MS patients in need of multidisciplinary treatment. The INTERMED domains show the area of the patient's vulnerability and care needs: especially the INTERMED's psychological and social domains may guide the clinician to deal with specific problems that complicate healthcare delivery.

Multiple sclerosis (MS) is the most common cause of neurological disability in young people.^{1,2} Characteristically, the course of the disease is highly variable and unpredictable, although, with time, about two thirds of patients pass into a progressive phase where a gradual accumulation of wide ranging, and often complex, disabilities occurs. These disabilities have a huge impact on the patient, family and society, affecting mood, relationships, employment, and social interaction. Not surprisingly, this results in huge cost to the society, much of which relates to indirect effects of the disease, including loss of employment for both patient and carer.

The recent development of disease modifying drugs has not eliminated the need for rehabilitative strategies in the management of MS. Rehabilitative techniques must be used to reduce disability and handicap and should include a wide range of interventions such as education, improving coping strategies, physical rehabilitation, or the set up of a network of community support. It is crucial to identify the optimal approach for individual patients, but so far there are few systematic data to guide patient referral.

In most specialised centres the required patient care needs, as well as the required treatment input and rehabilitation goals for individual patients, are based on a detailed assessment of physical, psychological, and social functioning by a multidisciplinary team. Such a team is, however, usually limited in the number of patients it can assess. Therefore, in many places access to a multidisciplinary team is restricted or only possible through long waiting lists. As a consequence, a simple and short instrument that would screen patients with respect to their needs and that could guide referral to the

multidisciplinary team, would be most welcomed and might increase the (cost) effectiveness of the assessment procedure.

Neither the Expanded Disability Status Scale (EDSS)³ nor the Guy's Neurological Disability Scale (GNDS),^{4,5} two instruments that measure disability in MS patients, give guidance with respect to rehabilitative strategies required. Despite the fact that the EDSS and GNDS are not developed to give guidance to rehabilitative strategies, we used these measures in this study for comparing with the INTERMED because the EDSS is an often applied outcome measure in clinical trials of MS and it seems possible that there is a connection between more disability (EDSS), especially self reported disability (GNDS), and the need for multidisciplinary treatment. In contrast with the EDSS and GNDS, the INTERMED has been defined to give guidance to the kind of (multidisciplinary) treatment a patient needs.

In this study we have investigated the INTERMED, an instrument that has been developed in the past years as a method to assess case complexity in order to organise coordinated and integrated health care.^{6,7} It is based on observations that comprehensive understanding of patients' needs increases effectiveness of healthcare delivery in several patient populations.^{8–11} The INTERMED is an observer rated instrument that classifies information from a structured and protocolled medical history taking into four domains: biological, psychological, social, and health care. Each domain is assessed in the context of time (history, current state, and prognosis),

Abbreviations: MS, multiple sclerosis; EDSS, Expanded Disability Status Scale; GNDS, Guy's Neurological Disability Scale

Table 1 INTERMED

Domains	History	Current state	Prognoses
Biological	- Chronicity - Diagnostic uncertainty	- Severity of illness - Diagnostic uncertainty	- Complications and life threat
Psychological	- Restrictions in coping - Premorbid psychiatric dysfunctioning	- Resistance to treatment - Severity of psychiatric symptoms	- Mental health threat
Social	- Restrictions in social integration - Social dysfunctioning	- Residential instability - Restrictions in social network	- Social vulnerability
Health care	- Intensity of prior treatment - Prior treatment experience	- Organisational complexity - Appropriateness	- Care needs

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which results in 20 variables (table 1). The different domain scores of the INTERMED show the area of the patient's vulnerability and care needs and give a direction for an integrated treatment plan. The specific variables force the clinician who rates the INTERMED to think about specific problems that complicate healthcare delivery, such as compliance, alcohol misuse, coping problems, need for social support and/or help at home, and psychiatric comorbidity. Giving global guidance with respect to therapeutic interventions required has been one of the important goals in the development of the INTERMED.

In the process of its development, attention has been directed to the reliability,⁶ validity,¹² and the clinical utility^{13–17} of the INTERMED. Reliability has been studied in terms of inter-rater agreement, as another important goal of the INTERMED was to improve communication between health care professionals. A first inter-rater reliability study⁶ suggested that some improvements should be made, which has led to a final version now being used in a number of studies. A recent study of the inter-rater reliability of this final version in a heterogeneous sample of patients with somatic illnesses, with two independent raters—a psychologist and a clinician nurse specialist—blindly rating patients based on a joint interview, resulted in a κ of 0.85, indicating very good agreement.¹⁸

Internal consistency has been studied as well as reliability coefficients (Cronbach's α), ranging from 0.75 to 0.92 in different patient samples.

Applications in other patient populations with somatic and psychosocial comorbidities, such as diabetes and advanced cancer have demonstrated the INTERMED's utility as measure for case complexity and resulting care needs.^{13–15} Furthermore, the INTERMED can be used to detect patients with a risk of decreased response to standard biomedical treatment, to design multimodal treatment, and to control for confounding variables.¹⁹

The objective of this study was to analyse the additional information obtained by the INTERMED in a cohort of MS patients compared with neurologist rating of neurological examination abnormalities (EDSS) and patient self report (GNDS), and to study correlations between these measures and healthcare needs as defined by a professional multidisciplinary team.

METHODS

Patients

One hundred consecutive newly referred patients fulfilling diagnostic criteria for MS,²⁰ who consulted the neurological outpatient clinic of the VU Medical Centre in the period March 1999 to November 2000 were included in this study. During this time period newly referred MS patients were referred to the multidisciplinary team without taking into account whether it was felt at the first visit there was a need for multidisciplinary assessment or not. Patients were diagnosed as

having relapsing-remitting (RR) (n=56), secondary-progressive (SP) (n=24), or primary-progressive (PP) (n=20) MS.²¹

Procedure

Patient care needs were assessed according to a standard procedure and discussed in a multidisciplinary team consisting of: neurologist, MS nurse, doctor of rehabilitation medicine, physiotherapist, occupational therapist, psychologist, and social worker. For each individual patient the multidisciplinary team defined a goal oriented treatment programme. In "simple cases" it would consist of continued care by only the neurologist and the MS nurse; in more complicated cases input of at least one of the other participating disciplines would be recommended, resulting in a really multidisciplinary rehabilitation approach.

In parallel, patients underwent INTERMED, EDSS, and GNDS examinations; the team did not know the results of these examinations at the moment they defined the treatment programme.

Detailed test procedures

The INTERMED form was filled in by the MS nurse on the basis of a structured medical history from the nurse's point of view. The four domain scores of the INTERMED (table 1) were obtained by adding the scores (0–3) of the five variables for each domain; the total INTERMED score is the sum score of the four domain scores (range 0–60). An independent psychologist (PdeJ) calculated the INTERMED (domain) scores and these were actively kept away from the multidisciplinary team.

Disability on the EDSS was assessed by well trained medical doctors under carefully standardised conditions; the EDSS is divided in 20 half points ranging from 0 (normal) to 10 (death attributable to MS). The GNDS score was based on a patient interview; each subcategory of the GNDS was scored separately, ranging from 0 (normal) to 5 (maximum help required). For creating the GNDS score, the sum score of the 12 subcategories was used, with a range from 0 (normal) to 60 (maximum possible disability).⁴

Data analysis

To study the relation between the scores on the various instruments and the patient healthcare needs, the recommended number of disciplines in the treatment programme as proposed by the multidisciplinary team was used. Analysis of difference in INTERMED, EDSS, GNDS sum score, and number of recommended disciplines for two different disability strata (EDSS ≤ 4.0 v EDSS > 4.0) was done using one way analysis of variance. Spearman's rank correlation coefficients (r) were calculated to assess the relation between the INTERMED sum score, its domain scores, EDSS, GNDS sum score, and total number of disciplines involved. In addition, Spearman's rank correlations were studied between age and

Table 2 Patient characteristics, age, and disease duration expressed as mean (SD). EDSS, GNDS sum score, INTERMED, INTERMED domains, and number of disciplines (besides neurologist and MS nurse) expressed as median (interquartile range)

	Total	Mild*	More disability†
Total	100	63	37
M	33	19	14
F	67	44	23
Age	40.6 (10.1)	37.0 (8.8)	46.7 (9.3)
Disease duration (y)	8.0 (7.8)	4.9 (5.7)	12.2 (8.4)
EDSS‡	4.0 (2.0–6.0)	2.5 (1.5–3.5)	6.5 (5.3–7.0)
GNDS§ sum score	13.5 (7.3–22)	10.0 (5.0–14.0)	23.0 (19.0–26.0)
INTERMED	14.0 (10.3–18.0)	12.0 (10.0–15.0)	18.0 (13.0–23.0)
Biological	7.0 (6.0–8.0)	7.0 (6.0–8.0)	8.0 (7.0–8.0)
Psychological	2.0 (1.0–4.0)	2.0 (1.0–3.0)	3.0 (1.0–5.0)
Social	1.0 (0.0–4.0)	0.0 (0.0–1.0)	4.0 (2.5–5.0)
Health care	3.0 (2.0–4.0)	2.0 (1.0–3.0)	4.0 (2.5–5.0)
Number of disciplines	1.0 (0.0–1.0)	1.0 (0.0–1.0)	1.0 (0.0–2.0)

*Mild disability = EDSS ≤4.0; †More disability = EDSS >4.0; ‡EDSS = Expanded Disability Status Scale; §GNDS = Guy's Neurological Disability Scale.

Table 3 Median scores on EDSS, GNDS sum score, and INTERMED per number of involved disciplines besides neurologist and MS nurse (interquartile range)

Number of disciplines	0 n=39	1 n=41	2 n=13	3 n=7
EDSS*	2.5 (1.5–4.5)	4.0 (2.8–5.8)	4.0 (1.8–5.5)	6.5 (6.0–7.5)
GNDS† sum score	10.0 (4.0–18.0)	12.0 (8.0–22.0)	17.0 (10.0–21.5)	26.0 (26.0–28.0)
INTERMED	12.0 (10.0–15.0)	15.0 (11.0–18.0)	17.0 (13.0–22.0)	20.0 (15.0–23.0)
Biological	7.0 (6.0–8.0)	7.0 (6.0–8.0)	8.0 (7.0–8.0)	8.0 (8.0–8.0)
Psychological	2.0 (1.0–3.0)	3.0 (1.0–5.0)	3.0 (2.0–3.5)	3.0 (1.0–5.0)
Social	0.0 (0.0–2.0)	1.0 (0.0–4.0)	3.0 (0.5–5.5)	4.0 (2.0–7.0)
Health care	2.0 (1.0–3.0)	3.0 (2.0–4.0)	4.0 (2.5–5.0)	4.0 (4.0–5.0)

*EDSS = Expanded Disability Status Scale; †GNDS = Guy's Neurological Disability Scale.

Table 4 Median scores on the INTERMED domains, EDSS, GNDS sum score, and INTERMED sum score per discipline involved (interquartile range)

	Biological	Psychological	Social	Health care	INTERMED	EDSS*	GNDS† sum score
Psychologist (n=29)	7.0 (7.0–8.0)	4.0 (3.0–5.0)	1.0 (0.0–4.0)	4.0 (2.5–4.5)	27.0 (13.0–20.5)	4.0 (3.0–6.3)	14.0 (7.5–24.5)
Social worker (n=9)	8.0 (8.0–8.0)	3.0 (2.0–5.0)	5.0 (4.0–6.5)	4.0 (3.5–4.5)	19.0 (18.0–23.0)	6.0 (1.8–7.0)	23.0 (7.5–29.0)
Physiotherapist (n=14)	7.5 (6.0–8.0)	2.5 (1.0–3.5)	1.0 (0.0–3.0)	3.0 (2.8–5.0)	15.0 (10.0–17.8)	4.3 (3.4–6.0)	16.0 (10.0–26.0)
Occupational therapist (n=25)	8.0 (7.0–8.0)	2.0 (1.0–3.0)	3.0 (0.0–4.5)	3.0 (1.0–4.0)	16.0 (12.5–19.5)	5.0 (3.3–6.5)	17.0 (12.5–26.0)
Rehabilitation (n=9)	8.0 (7.5–8.0)	3.0 (1.0–5.5)	3.0 (0.5–4.5)	4.0 (2.5–5.0)	16.0 (12.0–23.0)	6.0 (4.5–6.3)	23.0 (19.5–27.0)
No other disciplines (n=39)	7.0 (6.0–8.0)	2.0 (1.0–3.0)	0.0 (0.0–2.0)	2.0 (1.0–3.0)	12.0 (10.0–15.0)	2.5 (1.5–4.5)	10.0 (4.0–18.0)

*EDSS = Expanded Disability Status Scale; †GNDS = Guy's Neurological Disability Scale.

disease duration and number of involved disciplines. To account for the multiple correlations tested, we considered p values <0.01 as statistically significant and p values <0.05 as a trend only.

RESULTS

Patient characteristics, INTERMED sum scores, INTERMED domain scores, EDSS, and GNDS sum scores and number of disciplines involved are summarised in table 2 for the total population and for different disability strata. Sixty three patients had mild disability (EDSS ≤4.0) and 37 patients were moderate to severely disabled (EDSS >4.0). Mean (SD) age was 40.6 (10.1) years; 33% were male and 67% female, mean (SD) disease duration 8.0 (7.8) years. Median scores were 4.0 for the EDSS, 13.5 for the GNDS sum score, and 14.0 for the INTERMED. Significant differences were found between the two disability strata (mild or more disability) for GNDS sum score ($p<0.001$), INTERMED sum score ($p<0.001$), the INTERMED domains biological, social, and health care (for all three domains $p<0.001$), and number of proposed disciplines by the multidisciplinary team ($p<0.001$).

For a total of 61 patients, at least one other healthcare discipline besides neurologist and MS nurse was included in the treatment recommendation plan by the multidisciplinary team. Table 3 shows the median scores of the INTERMED sum score, EDSS, and GNDS sum score per number of disciplines proposed. As expected EDSS, GNDS sum score, and INTERMED sum scores were higher when more disciplines were involved.

Table 4 shows the median scores on the different INTERMED domains, INTERMED sum score, EDSS, and GNDS sum score per proposed discipline. Of the different disciplines, the intervention of a psychologist was most often recommended in the treatment plan of individual patients (in 29 cases), in these cases the median scores on the psychological domain of the INTERMED and the INTERMED sum score were highest and, remarkably, median EDSS and GNDS sum scores were lowest compared with cases when treatment intervention of another discipline was recommended.

Moderate correlations were found between the INTERMED sum score and both the EDSS ($r=0.59$; $p<0.01$) and the GNDS sum score ($r=0.60$; $p<0.01$) as well as the number of proposed disciplines ($r=0.41$; $p<0.01$) for the total population. The

Table 5 Spearman rank correlations between INTERMED, EDSS, GNDS sum score and INTERMED sum score, INTERMED domains, and number of involved disciplines for the total population

	INTERMED sum score	EDSS†	GNDS‡ sum score
INTERMED sum score	–	0.59**	0.60**
Biological	0.75**	0.52**	0.58**
Psychological	0.63**	0.24*	0.27**
Social	0.84**	0.61**	0.62**
Health care	0.81**	0.46**	0.47**
Number of disciplines	0.41**	0.32**	0.34**

**Correlation is significant at the 0.01 level; *correlation is significant at the 0.05 level; †EDSS = Expanded Disability Status Scale; ‡GNDS = Guy's Neurological Disability Scale.

number of disciplines showed lower correlations with both EDSS ($r=0.32$; $p<0.01$) and GNDS sum score ($r=0.34$; $p<0.01$).

All four INTERMED domains showed good correlations with the INTERMED sum score. Good correlations were also found between the social domain and both EDSS and GNDS sum score, and moderate correlations were found between the biological and healthcare domains and both EDSS and GNDS sum score. The psychological domain however showed no statistically significant correlation with the EDSS and only a weak but significant correlation with the GNDS sum score (table 5).

No statistically significant correlation was found between the number of proposed disciplines and age, whereas a weak correlation was found with disease duration ($r=0.31$; $p<0.01$).

DISCUSSION

In this cross sectional study we analysed the potential role of the INTERMED as an instrument that would help to screen individual patients to provide information to guide future interventions, by comparing it with the traditionally used neurologist rating of neurological examination abnormalities (EDSS), patient self report (GNDS), and the number of different disciplines being recommended in the treatment plan indicated by a multidisciplinary team.

Our data confirm that the INTERMED indeed gives complementary information when compared with the EDSS and the GNDS, especially because the INTERMED includes domains (that is, psychological and social) not or only partially represented in either EDSS or GNDS.

We found that the INTERMED was the best predictor for treatment decisions in a multidisciplinary rehabilitation focused approach. The INTERMED sum score showed the best correlation ($r=0.41$) with the total number of disciplines involved in the treatment plan of MS patients as indicated by the multidisciplinary team compared with both EDSS and GNDS. However, an overlap in the INTERMED sum score and number of disciplines involved existed, for example at INTERMED sum score 10 as well as 17 the number of proposed disciplines was 0, 1, or 2.

Analysing the four individual domains of the INTERMED showed an additional value of the INTERMED, especially the psychological domain, which is only partially or not at all represented in either the GNDS or the EDSS. This is shown by the fact that a weak, but statistically significant, correlation was found between the psychological domain and the GNDS and a trend only with the EDSS, whereas a good correlation was found with the INTERMED sum score.

It was striking to find the weak or even absent statistically significant correlations between the psychological domain score, and the GNDS sum score or the EDSS, especially in the light that the psychologist was the discipline most often recommended in the treatment plan as proposed by the

multidisciplinary team. These weak or absent correlations are most probably because of the fact that, mainly in early diagnosed MS patients who still have low disability (low EDSS and GNDS scores), psychological aspects, like acceptance of diagnose and coping strategies, are important features for which intervention by a psychologist can be indicated.

Although the EDSS and the GNDS do not incorporate the issue of social problems, their correlation with the social domain score of the INTERMED was statistically significant, even though not so high as for the INTERMED sum score. We assume that this is attributable to the fact that this domain reflects the level of functioning—that is, having a job or stable housing situation—which is often correlated to disability. If a patient does not have a job (which is more probable at higher EDSS scores), this influences the variable restrictions in social integration (at least 2 points) and restrictions in network (at least 1 point).

The social domain turned out to be a determinant for the total number of disciplines involved in the treatment of MS patients as advised by the multidisciplinary team. This is shown by the fact that the social domain score was higher when more disciplines were recommended. More specific, the social domain score seemed to be a predictor for a requirement of intervention by a social worker (table 4).

The biological domain of the INTERMED showed relatively high median scores as well as ceiling effects with little variation and a small interquartile range between the different disability strata as well as the total number and kind of disciplines recommended in the treatment plan as indicated by the multidisciplinary team. This is a result of the scoring rules of the INTERMED and the fact that MS patients suffer from at least one chronic condition that directly influences their scores on chronicity (at least a score of 2) and biological prognosis (at least a score of 2), therefore a score lower than 4 on the biological domain would not have been possible. Another problem is the fact that, for example, communication problems or dysphagia are scored in the biological domain and as there is ceiling effect, consequently these problems are not shown by the biological domain score. Communication and swallowing problems, however, were rare in our patient population (median scores on both GNDS subcategories speech and swallowing were 0.0 (IQR 0–1) and 1.0 (IQR 0–2) for the Brainstem Functional System of the EDSS).

In addition, most of the patients have experienced a period of diagnostic uncertainty, which is reflected in past or present diagnostic complexity in this domain. Obviously, this domain does not add new information as compared with the EDSS or the GNDS.

In conclusion, our study shows that the INTERMED (domain) scores provide complementary information when compared with either EDSS or GNDS. Specific domains of the INTERMED show the area of the patient's vulnerability and care needs, whereas the specific variables, especially the psychological and social domain, may guide the clinician to deal with specific problems that complicate healthcare

delivery. We would like to emphasise, however, that even though the INTERMED clearly is a promising screening instrument, it does not replace the need for multidisciplinary assessment: even though it identifies problem areas, it does not exactly indicate what the specific problems are and how they might be tackled.

To demonstrate the clinical usefulness of the INTERMED in MS patients in more depth, further studies will be necessary—that is, relating INTERMED scores to clinical decision making, to health care utilisation, and to outcome of intervention.

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