

How Does Fatigue Affect Communication?

The Influence of Fatigue on Cognitive, Physical, Psychosocial and Communicative Ability in Individuals With Multiple Sclerosis

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Fatigue and problems related to communication are common symptoms of multiple sclerosis (MS). However, no research has been conducted on how fatigue affects the communication of individuals with MS. For this study, the Fatigue Impact Scale (FIS) was supplemented with 20 statements concerning communication. Forty-four people with MS and 44 healthy controls completed the questionnaire. Results showed that individuals with MS experienced significantly greater problems caused by fatigue within all sub-areas (cognitive, physical, psychosocial and communicative) compared to the control group. No significant differences were observed in fatigue with regard to MS sub-type, gender, age, neurological disability, or medication. The major influence of fatigue was reported to be in the physical area, with less impact related to communication. Respondents who experienced communicative problems caused by fatigue also had problems with language comprehension and speech (dysarthria). Fifteen subjects with MS were randomly selected to participate in assessments of speech and language. As a whole, the group scored well on all tests suggesting relatively normal communication abilities. No clear correlation emerged between the participants' ratings on the FIS and its supplementary questions with the speech and language tests. However, participants who were in paid employment reported fewer areas of impact from fatigue. This study emphasizes the importance of using both subjective and objective measures to capture both speech and language problems in individuals with MS and also to establish the effect of fatigue on communication. Int J MS Care. 2004;6:39–51.

Introduction

Fatigue is the single most common complaint of individuals with MS, with a concomitant major impact on daily functioning and quality of life.^{1,2} The Multiple Sclerosis Council for Clinical Practice Guidelines³ has defined fatigue as “a subjective lack of physical and/or mental energy that is perceived by the individual or caregiver to interfere with usual and desired activities.” There are several different causes and types of fatigue, including disease process-related fatigue, fatigue related to concomitant infection or medications, fatigue of handicap, fatigue due to disordered or disrupted sleep patterns, and fatigue associated with depression or nerve fiber fatigue. The ability to communicate is also frequently affected in individuals with MS, along several different dimensions such as speech production and cognition-related abilities such as language.⁴⁻⁶

In addition to these studies of speech and language, interper-

sonal aspects—which would logically include communication—have received research attention. In the psychosocial field, a number of authors have highlighted deteriorating relationships as having a significant impact as a result of MS.⁷⁻⁹ It has been suggested that cognitive deficits can also cause communication problems and impinge on close relationships.¹⁰ Another group introduced the novel concept of interaction strain as a factor in social skills of people with MS,¹¹ while the psychosocial consequences for partners of people with MS have also been highlighted.¹² Despite this strong evidence of both the significant impact of fatigue and affected communication in MS, there have been no studies of the interaction of the two in this population.

Research outside the area of MS clearly establishes the relationship between fatigue and communicative difficulties. The motor effects of fatigue and “sense of effort” on the components of speech have been examined experimentally in both healthy populations^{13,14} and people with Parkinson's disease.¹⁵ Correlations between quality of the voice and fatigue have been found following laryngectomy,¹⁶ although some authors have postulated that an individual's response to fatigue, maladaptive or otherwise, and not just the fatigue effects themselves must be considered.¹⁷ The effects of fatigue on speech and listening capacity have also been studied in occupational settings.¹⁸⁻²⁰

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While these studies of largely unitary aspects of communication are useful, there are fewer reports of the effect of fatigue on overall communication such as interpersonal behavior. Some self-report studies highlight the impact of fatigue on psychosocial variables, for example in stroke and cancer, but fail to specify what these individual variables might be in terms of communication.^{21,22}

A more relevant study incorporating fatigue was conducted by O'Flaherty and Douglas,²³ who examined the interaction patterns of individuals with traumatic brain injury. The authors stated that the participants experienced significant communication difficulties which, in combination with other frequently reported problems such as fatigue, commonly generated unsatisfactory interpersonal communication experiences. These results point explicitly to the compounding difficulties fatigue would pose in a group of people already experiencing communication disorders.

In studies of MS, fatigue has been reported to affect speech and its motor control.²⁴ Logically, fatigue in MS has also been reported to limit social interaction and participation^{2,25,26} despite these authors' failure to specify communication itself.

However, the impact of this combination of factors in MS has perhaps best been expressed to date by Yorkston et al.²⁷ These authors conducted qualitative interviews with seven individuals with MS with questions about how everyday communication has changed as a consequence of MS. The combined effects of speech, language, and cognitive changes as well as fatigue were all implicated in limiting participation. As one informant reported, "I was minimizing my contacts. I found that social interactions were very exhausting. . .so I couldn't really be away from the house. And social situations in which a lot of interaction was required was very difficult for me."

Another person said, "Everything seemed to be magnified and I was just able to do less and less and less; I would find at night that [my husband] and I, we'd just sit and look at one another, rather than converse. And television became more of a focus point because it filled that emptiness."²⁷

It is clear therefore that both fatigue and cognitive-communication disorders are common in MS. The effects of fatigue on many aspects of everyday functioning have been considered, but no studies have specifically considered its effects on communication, other than aspects of motor speech abilities. Yet communication is at the core of personal relationships and social interaction. While we can predict what the motor effects of fatigue on speech might be, we have no knowledge of its perceived effects across the breadth of communication: voice, language construction, word choice, pragmatics, comprehension, expression and so on. Many clinicians working with people who have MS spend time counseling them about the disease's effects on their daily lives. These professionals currently have little empirical basis from which to initiate discussion of communication and fatigue issues from the individual's point of view.

The present study was divided into two parts. The questionnaire study was designed to explore the impact of fatigue on cog-

nitive, physical, psychosocial and communicative abilities, using the Fatigue Impact Scale^{28,29} supplemented by statements regarding communication (called the Communication Scale). Specifically, the following questions were asked:

1. Is there a significant difference between how individuals with MS perceive the impact of fatigue on cognitive, physical, psychosocial and communicative abilities compared to a control group?
2. Is the impact of fatigue perceived differently across domains (cognitive, physical, psychosocial and communicative)?
3. Is the impact of fatigue perceived differently depending on the individual's type of MS?

In the second part of the study, the speech and language performance study, a randomly selected subgroup of individuals with MS was assessed using tests of dysarthria and high-level language function, and also interviewed about perceptions of fatigue. The following specific questions were asked:

1. Is there a correlation between perceived effects of fatigue on communication and actual test performance?
2. Is there a correlation between perceived effects of fatigue as measured by the questionnaire in the first part of the study and the results of the interview on perceptions of fatigue?
3. Is there a correlation between test performance and results of the interview on perceptions of fatigue?

Materials and Methods

Fatigue Impact Scale. The Fatigue Impact Scale (FIS)^{28,29} is a self-report questionnaire that assesses the effects of fatigue on quality of life. The FIS includes three subscales to assess perceived fatigue impact on cognitive functioning (10 items), physical functioning (10 items), and psychosocial functioning (20 items). Patients or informants are asked to assess how much of a problem fatigue has been for the past month in relation to the 40 statements. For example, "Because of my fatigue I feel like I cannot think clearly" (cognitive), "Because of my fatigue I am less motivated to do anything that requires physical effort" (physical), and "Because of my fatigue I worry about how I look to other people" (psychosocial). The assessment is made using a five-point scale ranging from 0 (no problem) to 4 (extreme problem), the maximum FIS score being 160. FIS was reported to have high internal and external validity and to be a reliable tool in measuring patients' attribution of functional limitations to symptoms of fatigue. The translation of the scale to Swedish was done in collaboration by a team of clinicians (neuropsychologists and speech-language pathologists) at the Department of Neuropsychology and the Department of Neurologopedics at Sahlgrenska University Hospital, Göteborg.

Communication Scale. FIS was supplemented by 20 statements concerning the effects of fatigue on communication developed for the purpose of this study. These statements were designed to reflect different aspects of communication; cognition and language (six items), articulation and voice (six items), and pragmatics (eight items). For example, "Because of my fatigue I have difficulty finding words when I talk" (cognition and language),

“Because of my fatigue my speech is slurred” (articulation and voice), and “Because of my fatigue I don’t have enough energy to concentrate on what is being said” (pragmatics).

The questionnaire ended with an open question: “Of the above, what items give you problems even when you are not tired (i.e., independent of fatigue)?” The aim of the last question was to generate discussion concerning whether and how fatigue was related to the problem areas.

A pilot study conducted with five healthy individuals clarified difficulties arising from the wording in the questionnaire. The project was approved by the Research Ethics Committee at the Medical Faculty of Göteborg University.

Subjects

Questionnaire study. Sixty-two individuals with MS were invited to participate during their scheduled appointments at the MS center at Sahlgrenska University Hospital. Forty-four complete questionnaires were returned, representing a 71% response rate. Medical charts were also reviewed to provide information about MS type, current medication and the Expanded Disability Status Scale (EDSS).³⁰

There were 31 women and 13 men included in the questionnaire study; 33 had relapsing-remitting MS (RRMS) while nine had secondary progressive and two had primary progressive MS. Ages ranged from 21 to 74 years, with a mean age of 42.2 years (SD 12.4). All individuals had been assessed using EDSS and were grouped according to the following criteria:

- EDSS I: Normal neurological status, EDSS = 0
- EDSS II: Moderate neurological disability, patient can walk more than 500 meters, EDSS = 1 to 3.5
- EDSS III: Moderate neurological disability, patient can walk 100 to 500 meters without support or rest, EDSS = 4 to 5.5
- EDSS IV: Severe neurological disability, patient walks with support or uses a wheelchair, EDSS = 6 to 10

The control group was selected in the university community and matched for age and gender. In addition to answering the questionnaire, they were also asked about current medication.

Speech and language performance study. Fifteen randomly selected individuals with MS from the questionnaire study were invited to participate in the second study, which included tests of speech and language function. The group included 11 women and four men with a mean age of 41.2 years (range 22 to 56; SD 11.6).

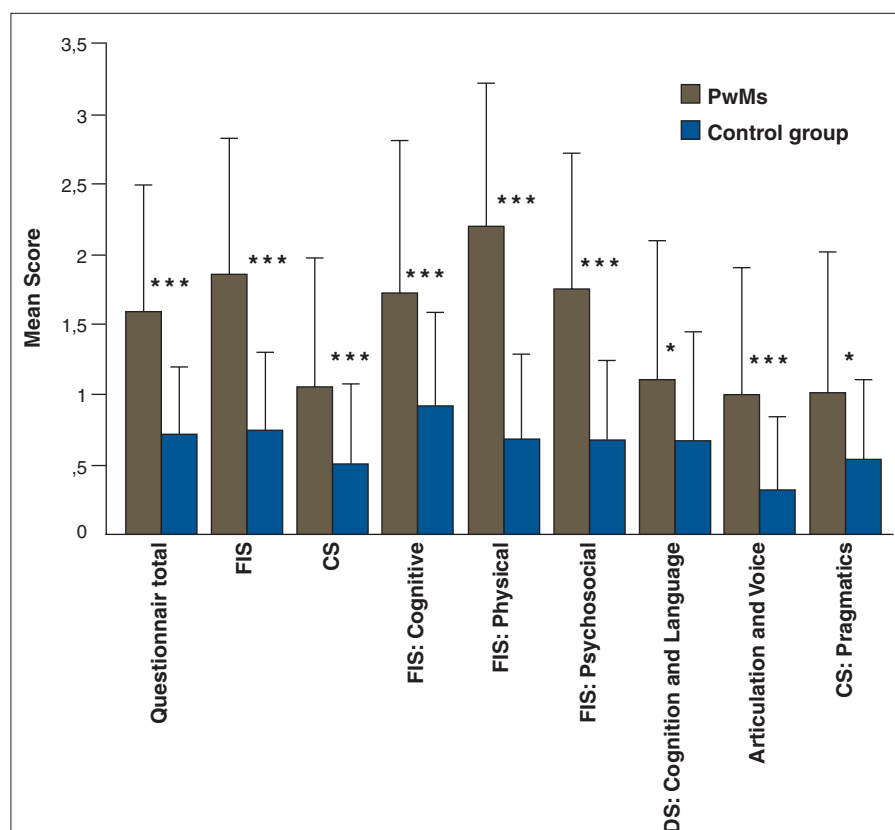


Figure 1

Mean scores on the Fatigue Impact Scale (including means on the subtests cognitive, physical, and psychosocial functioning) and mean scores on the Communication Scale (including the subscales on cognition and language, articulation and voice, and pragmatics) for the group of people with MS (PwMS) and the control group. The scale ranges from 0 = no problem to 4 = extreme problem. Paired t-tests, *** $P \leq 0.001$, * = $P \leq 0.05$.

Mean disease duration was 10.6 years (range 1 to 46; SD 11.1). Ten participants had RRMS while five had SPMS. Subjects were included for this part of the study on the basis that they had good hearing and vision (with correction), no other neurological damage or disease, and Swedish as their first language.

Tests of Speech and Language Function

Clinical dysarthria test procedure. The clinical dysarthria test procedure was developed and published in Sweden and includes subtests on respiration, phonation, oral motor performance, articulation, prosody, and intelligibility.³¹ The test protocol consists of 54 test items, scored on a five-point interval scale, ranging from 0 (corresponding to no or Insignificant deviation) to 4 (very severe deviation or no function). The subtest “Respiration” includes seven test items, for example maximum prolongation of a voiceless fricative s, and sudden loudness increase. The subtest “Phonation” also includes seven test items, for example to sustain maximally the vowel a, and items to test maximum variation of pitch. Oral motor performance includes a total of 24 test items divided into four sections reflecting the motor function of the lips, the jaw, the tongue,

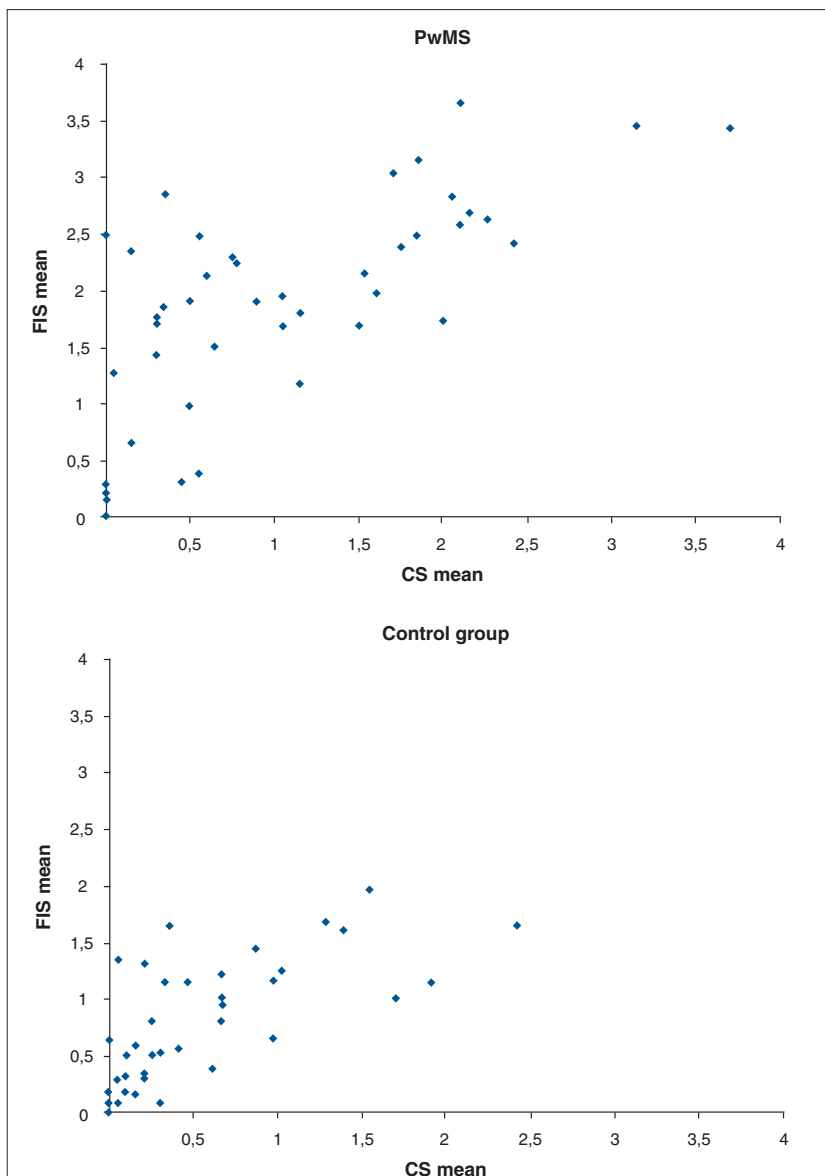


Figure 2
 Correlation between Fatigue Impact Scale (FIS) and Communication Scale (CS) for the group of people with MS (PwMS) and the control group. Correlations calculated using Pearson's correlation coefficient (PwMS $r = 0.708$, control group $r = 0.721$, both significant at the 0.01 level).

and the soft palate. One type of task is rating the speed and regularity of syllable repetitions (oral diadochokinesis). Articulation includes seven phonetically varied test sentences. The last two subtests, "Prosody" and "Intelligibility," include nine test items, such as contrastive stress and rate of speech. Intelligibility is both globally rated in continuous speech as well as calculated as the percentage of correctly transcribed one- and two syllable words and sentences. The last subtest also includes the reading of a standard text.

Standardized instructions and scoring procedures were followed. Each mean subtest score is subsequently added up and divided by six (the number of subtests) to form a mean dysarthria

score (ranging from 0 to 4, where 0 corresponds to No deviation and 4 to Very severe deviation or no function).

Tests of high-level language. Commonly used aphasia tests are not sensitive enough to detect high-level or subtle language disorders. The only material available in Swedish is the "Test battery for assessment of high-level language disorders." In its current form, the test battery consists of one test (BeSS, *Bedömning av subtila språkstörningar*, Assessment of subtle language disorders) comprising seven subtests. This test was developed at the Department of Logopedics and Phoniatics, Göteborg University, Sweden³² and was used in pilot study of individuals with MS.³³ The test originally included nine subtests. As a result of the pilot study, the test was modified and four complementary tests were added to form the final test battery.

In BeSS, the performances are judged using three point scale: zero, one or a maximum of three points. This scoring system is also used in the Test of Language Competence (TLC).³⁴ This scoring system was chosen because having a gap between one and three points would make it easier to differentiate between individuals giving slightly deviant answers and those giving completely correct responses. Some qualitative information was also taken into consideration in scoring procedures on most subtests, for instance phonemic and/or semantic paraphasias, syntactically and/or semantically deviant answers, and circumlocutions. All subtests except repetition have a time restriction for the test items, in order to identify individuals with answering latency. The seven subtests included in BeSS are:

1. Repetition of long sentences (10 items)

Sentences of main clauses and subordinate clauses consisting of nine to 16 words each, 15 to 24 syllables in length are read once to the subjects. The complexity of the sentences is such that they could

be found in a daily newspaper or a contemporary novel. To get full score, the subject needs to repeat a sentence exactly as given. Example: "Erik and Mats were leaning over a game of chess, which seemed to have been going on forever."

2. Recreating sentences (10 items)

The subject is presented with three key words from a given context and then requested to form an utterance (something someone could have said) including these words. Scoring is based on syntactic, semantic and pragmatic correctness. Example: Context: at the restaurant. Words: or, pie, have. Possible answer: Would you like to have a pie or a sandwich?

3. *Making inferences (7 short passages)*

In these stimuli of increasing length and complexity, the subject is allowed to both read and hear the passage, after which one or two questions are asked that require inferential reasoning. If the subject needs a clue, the score is reduced. Example: “Evert and Mona had coffee at the kitchen table. The curtains were blowing in the wind. Mona put on a cardigan and said, ‘Oh, it’s chilly.’ Evert helped himself to some cookies. Question: What did Mona want Evert to do? Possible answer: Close the window, hug her.”

4. *Comprehension of logico-grammatical sentences (10 items)*

This subtest assesses the comprehension of complex grammatical constructions, for example passive voice, inverted sentences, instructions in several steps and double negations. The sentences are only presented verbally and read twice to the subject. The included sentences are influenced by the work of Luria.³⁵ Example: “Tell me if the mother’s sister and the sister’s mother are two individuals or one and the same.”

5. *Comprehension of ambiguous sentences (lexical and syntactical; 10 items)*

At least two different meanings in each sentence are presented verbally and visually. Six of the sentences contain lexical ambiguities and four contain syntactical. The subject is asked to give two possible explanations of the sentence. No intonation or phrasing cues are given. Example: “He likes Malin more than Robert.” Correct answer: (a) He likes Malin more than he likes Robert, (b) He likes Malin more than Robert does.

6. *Comprehension of metaphors (10 sentences)*

Well-known Swedish metaphorical expressions are included and the subject is asked to explain their meaning. Literal explanations are not given any points. (Example: “She put her legs on her back,” i.e., she ran).

7. *Word definitions (10 items)*

The subject is asked to give an as accurate and precise definition of the stimulus word as possible. Examples: trauma, reject.

The four tests added to complement BeSS are:

1. *Word fluency test*

Three phonemic categories (f, a, and s) and one semantic category (animals) are used. The subject is asked to name as many words as possible from the given category within one minute.

2. *Boston Naming Test (BNT)³⁶*

BNT is a confrontation naming test including 60 pictures. Phonemic cues are given if needed. If the subject is misinterpreting the picture, a semantic cue can also be given.

3. *Sentence analysis³⁷*

Eighteen sentences, varying in length between two and nine words, are presented verbally to the subject. The task is to specify how many words are included in each sentence. Examples: “Put on very warm clothes.” “More than one wanted to be in the group.”

4. *Morphological completion³⁷*

In this test the task is to complete words with the missing morphemes. In five cases the beginning of a word is given and in 11 instances the end of the word is given. The tasks are presented verbally.

Examples: drott- (expected answer drottning – queen), –vändig (expected answer nödvändig – necessary).

Procedure. The speech and language assessments were conducted in a quiet room at the Department of Logopedics and Phoniatics at Sahlgrenska University Hospital. Two of the authors assessed all 15 participants. Initially, the participants answered questions about reading habits, number of years in education, whether they worked, etc. Also, the participants’ answers to the open question in the Communication Scale (“Of the above, what items give you problems even when you are not tired—i.e. are independent of fatigue?”) were used as starting points for a discussion about communication and fatigue. Subsequently, the assess-

Table 1. Comparison of Means (t-values and significance levels) of MS Types RRMS (n = 33) vs. SPMS (n = 9) vs. control group (CG, n = 44), calculated using unpaired t-tests

	RRMS compared to CG		SPMS compared to CG	
	t-value	Sign level (P value)	t-value	Sign level (P value)
Questionnaire total	-5.89	≤ 0.001		
FIS	-6.72	≤ 0.001		
CS	-2.98	≤ 0.01		
FIS: cognitive	-4.62	≤ 0.001		
FIS: physical	-7.71	≤ 0.001	-3.52	≤ 0.01
FIS: psychosocial	-6.54	≤ 0.001		
CS: cognition and language	-2.39	≤ 0.05		
CS: articulation and voice	-3.44	≤ 0.001	-2.60	≤ 0.05
CS: pragmatics	-2.41	≤ 0.05		

ments were carried out, with subtests presented in random order with frequent breaks to avoid order effects and fatigue. After the test session, the two assessors compared notes and in cases of disagreement they reached a consensus.

Analysis

Questionnaire study. Mean scores on the FIS (including means on the subtests cognitive, physical, and psychosocial functioning) and mean scores on the Communication Scale (including the subscales on cognition and language, articulation and voice, and prag-

Table 2. Speech and Language Test Results for 15 subjects in second study

Subject	FIS (0-4)	CS (0-4)	Dysarthria test (0-4)	BeSS (%)	FAS (wds/min)	BNT (# wds)	Sentence analysis	Morphologic completion
1	3.45	3.15	0.47↑	43↓	8.7	48	78	31↓
2	3.15	1.85	0.04	90	14.0	51	100	81
3	1.80	1.15	0.53↑	99	19.7	56	89	100
4	1.50	0.65	0.12	99	17.7	56	85	100
5	2.58	2.1	0.06	88	19.0	43	91	62↓
6	3.03	1.7	0.22	87	11.0	52	94	71↓
7	1.85	0.35	0.06	86	11.3	49	96	85
8	1.18	1.15	0.58↑	60↓	5.7	40	81	50↓
9	1.68	1.05	0.12	94	21.3	54	100	94
10	0.98	0.50	0.07	97	15.0	57	100	100
11	2.83	2.05	0.06	87	10.3	54	100	81
12	0.65	0.15	0.04	94	22.3	54	96	96
13	1.9	0.5	0.17	80	13.0	52	94	83
14	2.48	0.55	0.11	85	16.0	55	100	88
15	2.50	0.00	0.02	85	13.0	48	96	96
Mean	2.10	1.13		85%	14.5	51	93	81↓
SD	.84	.88		15%	4.8	5	7	20

↑↓ = non-normal values compared to published data on control subjects.

matics) were related to age, gender, MS type, medication and EDSS group. Differences between the MS group and the control group as well as between the different subscales were established using paired t-tests. Differences related to MS type, gender, EDSS groups and medication were established using unpaired t-tests. Correlations with age and within subscale means were calculated using Pearson's r correlation coefficient.

Speech and language performance study. Due to the small number of participating subjects, correlations were calculated using Spearman Rank Order correlation.

Results

Questionnaire study. Figure 1 shows the mean scores on the FIS including cognitive, physical, and psychosocial functioning subscales and mean scores on the Communication Scale (including the subscales on cognition and language, articulation and voice, and pragmatics) for the individuals with MS and the control group. Scores from the subjects with MS were significantly higher than those of the control group on all subscales as well as the FIS, the CS, and the entire questionnaire. That is, individuals with MS experienced significantly more problems related to fatigue in all areas compared to healthy controls.

Standard deviations were generally high in both groups. The subscale physical functioning contained mean scores ranging between 0 and 3.9 and "cognition and language" scores between 0 and 4. A statistical comparison of subscales showed that individuals with MS experienced significantly greater problems with fatigue related to physical functioning than to any other area ($P = 0.001$).

FIS scores were significantly higher than Communication Scale scores (paired t-test, $P = < 0.001$); 91% of the individuals with MS and 86% of healthy controls rated the items on the FIS higher than the ones on the CS. However, there was a significant correlation ($P = < 0.01$) between the FIS and the CS scores for both groups (Figure 2), $r = 0.708$ MS group and $r = 0.721$ control group, respectively.

There were no significant correlations between age and any of the scales or subscales, nor any significant differences depending on gender or medication that could possibly be fatigue inducing. There were no significant differences between the four different EDSS groups and perceptions of fatigue related problems. Comparing MS type, the group with relapsing-remitting MS generally experienced greater problems compared to the group with secondary progressive MS, but this difference was not statistically

significant. However, comparing each of the two groups with the control group, it became evident that the relapsing-remitting group experienced significantly more problems in all areas compared to the control group, while the secondary progressive MS group perceived fatigue to have a major impact on physical functioning (FIS) and articulation and language (CS; Table 1).

The MS group had the opportunity to answer an open question ("Of the above, what items give you problems even when you are not tired, i.e. are independent of fatigue?"). Twenty-one responses were obtained (7 men and 14 women). Six individuals indicated that the physical problems were evident even when they were not tired. Cognitive problems were perceived as being unrelated to fatigue by four persons and psychosocial problems by another four persons. Six individuals indicated that they experienced communication problems unrelated to fatigue. These problems were dysarthria (1), word finding difficulties (3), and cognitive-linguistic and/or pragmatic difficulties (2).

Speech and language performance study. Results of the questionnaire as well as those of the assessments for the 15 randomly selected participants in the speech and language performance study are presented in Table 2. However, means on FIS and CS are slightly higher in this group than in the questionnaire study. Only participants 1, 3, and 8 had a minimal dysarthria according to published norms,^{5,38} and only participant 1 and 8 had a mean on BeSS that was lower than an age matched control group.³⁹ Results on the word fluency test FAS were in accordance with other published studies.³⁹⁻⁴¹ Mean results on Boston Naming Test were slightly lower (1 to 5

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words) than in other comparable studies.^{39,42,43} The present results on sentence analysis were within normal limits but the mean results on morphological completion were significantly lower.³⁹

Participants 1 and 8 had the lowest scores on FAS, sentence analysis and morphological completion. Participants 5 and 8 had the lowest results on BNT.

Because overall results on speech and language performance were in most cases normal, no statistical calculations were made comparing test results with FIS and CS. However, a careful review of the results as well as the responses to initial questions led to the finding that employment correlated significantly with the scores on FIS ($r = 0.545$; $P = 0.036$) and CS ($r = 0.824$; $P < 0.000$; Figure 3).

Discussion

This study has shown that individuals with multiple sclerosis experience significantly greater impact of fatigue on their cognitive, physical, psychosocial, and communicative functioning compared to control subjects. This is in accordance with previous findings, that MS fatigue affects cognition,⁴⁴ physical performance,²⁵ psychosocial functioning and communication.²⁷

Results also showed that there was a large range of perceived severity of fatigue impact within the MS group but also within the control group. Differences in perceived impact of fatigue were not due to type of MS, gender, age or whether they were on fatigue inducing medication or not. In addition, degree of neurological disability as measured by EDSS did not correlate to perceived impact of fatigue. Other studies have also shown, that perceived

fatigue is unrelated to EDSS.^{2,45,46} Few studies have compared the type of MS and fatigue, and existing results have been conflicting.^{28,45}

In the present study, individuals with RRMS estimated their fatigue-related problems to be more severe than the individuals with SPMS both on Fatigue Impact Scale and on Communication Scale although differences were not significant. However, individuals with RRMS experienced significantly more severe problems in all areas compared to control subjects, whereas the individuals with SPMS only had significantly larger problems in physical functioning and articulation and voice. One conceivable reason for this could be that those with RRMS are living a more active life and therefore may be more inclined to notice the effects of fatigue compared with individuals who had to restrict their social life and expectations due to more persistent and severe symptoms of the illness. Fisk and colleagues²⁸ have shown that fatigue can be the single most functionally restricting symptom experienced by people with otherwise limited neurological involvement. The methodology in selecting patients for the current study may also have contributed, in that the individuals with RRMS who regularly attend the MS center have more problems, while the opposite can be true for the individuals with SPMS. The individuals with SPMS with the least problems might be fit enough to visit the center, while the more disabled are the subject of other types of interventions such as home-based care.

Other aspects may explain the broad range of fatigue related problems. Monks,⁴⁷ Schwartz,²⁶ and Vercoulen² stressed the relation between perceived fatigue and the feeling of having control

over one's own life situation. A continuous need to adapt to an unpredictable feeling of fatigue restricts a person's quality of life and affects his or her mental status.²⁷⁻²⁹ Questionnaires regarding locus of control might be a valuable addition to the assessment battery needed to describe the range of problems perceived by individuals with MS. Another factor that might be causing fatigue is of course disrupted sleeping habits, which, according to Leo and colleagues⁴⁸ and Saunders et al⁴⁹ is common and can con-

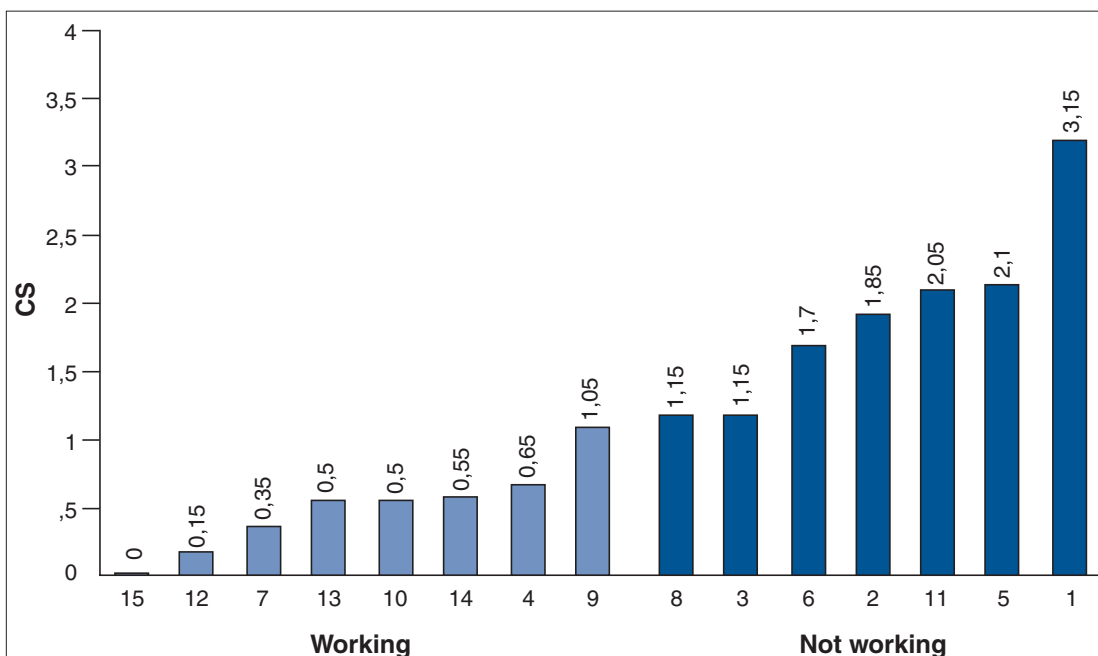


Figure 3

Correlation between results on Communication Scale (CS) and whether the subjects were working or not working.

The 15 participants are rank ordered according to results on CS.

tribute to perceived fatigue in MS.

The correlation between FIS and the Communication Scale (CS) confirms that individuals who suffer from effects of fatigue generally experience problems in a number of different areas and that the three aspects of FIS (cognitive, physical and psychosocial function) are all important ingredients in successful communication.^{50,51}

Our results showing higher ratings for fatigue on the FIS rather than the Communication Scale may have several explanations. One is that communicative problems may not be as apparent to the individual due to social restrictions and avoidance behaviors. With a limited number of opportunities for social interaction and fewer new acquaintances, the risk of communicative breakdown is lower. Another explanation might be cognitive impairment and resulting reduced insight. Foley⁵⁰ stressed that cognitive impairment might influence communication. Furthermore, individuals who are noticed to considering unitary aspects of communication may not attribute difficulties to these when questioned.

The MS group experienced more severe problems in physical functioning compared to the other areas. Krupp⁴⁶ pointed out that physical ability is severely affected by fatigue. However, the equivalent area in CS (articulation and voice) was reported to cause the least problems compared to pragmatics and language. This was unexpected, since dysarthria is a well-known symptom of MS. It does correspond with the findings of Yorkston²⁷ and Hinchcliffe⁵¹ who called attention to other symptoms of communicative problems in individuals with MS.

The 15 individuals randomly selected for the speech and language performance study rated their problems related to fatigue somewhat differently compared to the entire group of 44 individuals (FIS 2.10 and CS 1.13 in the speech and language performance study compared to FIS 1.89 and CS 1.05 in the questionnaire study). The group's mean dysarthria score (0.18) is below published norms.^{5,38} and consequently they were considered nondysarthric. The group was also within the normal range in their performance on the tests of high-level language,³⁹ FAS⁴⁰ and Boston Naming Test.⁴² Participants 1 and 8 had the lowest results on FAS, sentence analysis and morphological completion and participants 5 and 8 had the lowest results on BNT.

Even though the 15 subjects as a group performed within normal limits, seven of them reported communication problems that were independent of fatigue (open question) and that these problems were caused by the disease. All except one reported that fatigue was aggravating the problems. The individuals particularly mentioned indistinct and slow speech, long pauses, word-finding difficulties and reading comprehension difficulties.

Post-hoc analysis revealed that whether the participants were in paid employment or not had a significant correlation with the FIS and CS ratings. These results can be interpreted in two ways. Firstly, fewer disease-related problems could increase the likelihood of employment. Likewise could fewer disease-related problems imply that fatigue is also less of a problem. Secondly, the par-

ticipants who work might be less affected by their disease and fatigue may not cause as big a problem for them. Participating in professional activities might prevent the illness from dominating everyday life. This is in agreement with Krupp,⁵² who noted that "affected persons continue to report fatigue as being the primary factor that prevents them from working."

Clinical Implications

Fatigue is subjective and invisible. The experience of how fatigue may influence one's active participation in communicative interaction can only be determined from what is termed the insider's perspective. Many previous examinations have involved clinicians' assessment, that is, from the point of view of the outsider, which will not yield the full picture of individuals' reported physical and psychosocial experiences.⁵³ Hall Lord et al⁵⁴ reported discrepancies between clinical staff perceptions of patients' reports of subjective experiences (pain, discomfort, fatigue, and distress) and those of the patients. Results showed that staff tended to underestimate patients' subjective experiences of these factors.

Researchers have come to recognize therefore the importance of self-report measures, and not just observer or objective accounts of illness. And, while the relationship between social functioning and fatigue has been established by a growing body of research principally using quality of life instruments,⁵⁵ previous research in MS has not targeted the relationship between more specific aspects of communication and fatigue from the communicator's viewpoint.

In the current study the subjects' overall reaction and their responses to this investigation revealed that they perceived the questions as being important. It is evident that the speech-language pathologist's assessment battery should include a motor speech investigation as well as assessments of other aspects of language comprehension, language production and language use. In order to better meet the needs of individuals with MS, it is imperative that speech and language tests are complemented with patient-centered questionnaires regarding fatigue, sleeping habits and quality of life. The Multiple Sclerosis Council for Clinical Practice Guidelines³ has suggested the "Fatigue Questionnaire" and the "Sleep Questionnaire." The guidelines also include the use of an activity diary, which can be used as a starting point for intervention regarding fatigue-related problems in MS.

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References

1. Bakshi R, Shaikh ZA, Miletich RS, et al. Fatigue in multiple sclerosis and its relationship to depression and neurologic disability. *Mult Scler*. 2000;6:181-185.
2. Vercoulen JHMM, Hommes OR, Swanink MA, et al. The measurement of fatigue in patients with multiple sclerosis. *Arch Neurol*. 1996;53:642-649.
3. Multiple Sclerosis Clinical Practice Guidelines. 1998; Fatigue and multiple sclerosis: evidence-based management strategies for fatigue in multiple sclerosis. Washington, DC: Paralyzed Veterans of America.

4. FitzGerald FJ, Murdoch BE, Chenery HJ. Multiple sclerosis: Associated speech and language disorders. *Austr J Human Commun Dis.* 1987;15:15-33.
5. Hartelius L, Runmarker B, Andersen O. Prevalence and characteristics of dysarthria in a multiple sclerosis incidence cohort; in relation to neurological data. *Folia Phoniatica et Logopaedica.* 2000;53:160-177.
6. Murdoch BE, Theodoros DG (Eds). *Speech and Language Disorders in Multiple Sclerosis.* London: Whurr Publishers, 2000.
7. McCabe M, McDonald E, Deeks A, et al. The impact of multiple sclerosis on sexuality and relationships. *J Sex Research.* 1996;33:241-248.
8. Mohr D, Dick L, Russo D, et al. The psychosocial impact of multiple sclerosis: exploring the patient's perspective. *Health Psychol.* 1999;18:376-382.
9. Murphy N, Confavreux C, Haas J, et al. Quality of life in multiple sclerosis in France, Germany, and the United Kingdom. *J Neurol Neurosurg Psychiatry.* 1998;65:460-466.
10. Gilchrist AC, Creed FH. Depression, cognitive impairment and social stress in multiple sclerosis. *J Psychosom Res.* 1994;38:193-201.
11. Gordon P, Lam C, Winter R. Interaction strain and persons with multiple sclerosis: Effectiveness of a social skills program. *J Appl Rehabil Counseling.* 1997;28:5-11.
12. Knight R, Devereux R, Godfrey H. Psychosocial consequences of caring for a spouse with multiple sclerosis. *J Clin Exper Neuropsychol.* 1997;19:7-19.
13. Kuehn DP, Moon JB. Induced fatigue effects on velopharyngeal closure force. *J Speech Language Hearing Res.* 2000;43:486-500.
14. Somodi LB, Robin DA, Luschei ES. A model of "sense of effort" during maximal and submaximal contractions of the tongue. *Brain and Language.* 1995;51:371-382.
15. Solomon N, Robin D, Lorell D, et al. Tongue function testing in Parkinson disease: indications of fatigue. In Till J, Yorkston K, Beukelman D (eds). *Motor Speech Disorders: Advances in Assessment and Treatment.* Baltimore, MD: Paul H. Brookes. 1994;147-160.
16. Ackerstaff AH, Hilgers FJM, Aaronson NK, Balm AJM. Communication, functional disorders and life-style changes after total laryngectomy. *Clin Otolaryngol.* 1994;19:295-300.
17. Kostyk BE, Rochet AP. Laryngeal airway resistance in teachers with vocal fatigue: a preliminary study. *J Voice.* 1998;12:287-299.
18. Ivarsson US, Arlinger SD. Speech recognition in noise before and after a work day's noise exposure. *Scandinavian Audiology.* 1994;23:159-163.
19. Milosevic S. Drivers' fatigue studies. *Ergonomics.* 1997;40:381-389.
20. Whitmore J, Fisher S. Speech during sustained operations. *Speech Communication.* 1996;20:55-70.
21. Ingles JL, Eskes GA, Phillips SJ. Fatigue after stroke. *Arch Phys Med Rehabil.* 1999;80:73-78.
22. Osoba D, Aaronson NK, Muller M, et al. Effect of neurological dysfunction on health-related quality of life in patients with high-grade glioma. *J Neurooncology.* 1997;34:263-278.
23. O'Flaherty CA, Douglas JM. Living with cognitive-communicative difficulties following traumatic brain injury: using a model of interpersonal communication to characterize the subjective experience. *Aphasiology.* 1997;11:889-911.
24. Yorkston KM, Miller RM, Strand EA. *Management of Speech and Swallowing in Degenerative Diseases.* Tucson, AZ: Communication Skill Builders, 1995.
25. Krupp LB, LaRocca NG, Muir-Nash J, Steinberg AD. The fatigue severity scale: application to patients with multiple sclerosis and systemic lupus erythematosus. *Arch Neurol.* 1989;46:1121-1123.
26. Schwartz CE, Coulthard-Morris L, Zeng Q. Psychosocial correlates of fatigue in multiple sclerosis. *Arch Phys Med Rehabil.* 1996;77:165-170.
27. Yorkston KM, Klasner ER, Swanson K. Communication in context: A qualitative study of the experiences of individuals with multiple sclerosis. *Am J Speech Lang Pathol.* 2001;10:126-137.
28. Fisk JD, Pontefract A, Ritvo PG, et al. The impact of fatigue on patients with multiple sclerosis. *Can J Neurol Sci.* 1994;21:9-14.
29. Fisk JD, Ritvo PG, Ross L, et al. Measuring the functional impact of fatigue: initial validation of the fatigue impact scale. *Clin Infect Dis.* 1994;19:79-83.
30. Kurtzke JF. Rating neurologic impairment in multiple sclerosis: an expanded disability status scale (EDSS). *Neurology.* 1983;33:1444-1452.
31. Hartelius L, Svensson P. *Dysarthrietest.* Stockholm: Psykologiförlaget, 1990.
32. Brunnegård K, Laakso K. Assessing high-level language: The construction of a new test battery and the assessment of a group with multiple sclerosis. Unpublished Master's thesis, Department of Logopedics and Phoniatrics, Göteborg University, Göteborg, Sweden, 1998.
33. Laakso K, Brunnegård K, Hartelius L, Ahlsén E. Assessing high-level language in individuals with multiple sclerosis: a pilot study. *Clin Linguist Phonetics.* 2000;14:329-349.
34. Wiig EH, Secord W. *Test of Language Competence,* Expanded Edition. New York: Psychological Corporation, 1989.
35. Luria AR. *Higher Cortical Functions in Man.* New York, NY: Basic Books, 1966.
36. Kaplan E, Goodglass H. *Boston Naming Test.* Philadelphia: Lea Febiger, 1983.
37. Elbro C. *Differences in Dyslexia. A Study of Reading Strategies and Deficits in a Linguistic Perspective.* Copenhagen: Munksgaard, 1990.
38. Hartelius L, Svensson P, Bubach A. Clinical assessment of dysarthria: performance on a dysarthria test by normal adult subjects, and by individuals with Parkinson's disease or with multiple sclerosis. *Scand J Logopedics and Phoniatrics.* 1993;18:131-141.
39. Holmbo E, Olsson M. En äldre normalgrupps prestation på Testbatteri för Bedömning av Subtila Språkstörningar – relaterat till ålder, utbildning och kön. Göteborg: Avdelningen för logopedi och foniatri. Unpublished Master's thesis, 2000.
40. Loonstra AS, Tarlow AR, Sellers AH. COWAT metanorms across age, education, and gender. *Appl Neuropsychol.* 2001;8:161-166.
41. Piatt AL, Fields JA, Paolo AM, et al. Lexical, semantic, and action verbal fluency in Parkinson's disease with and without dementia. *J Clin Exper Neuropsychol.* 1999;21:435-443.
42. Marien P, Mampaey E, Vervaeke A, et al. Normative data for the Boston Naming Test in native Dutch speaking Belgian elderly. *Brain and Language.* 1998;65:447-467.
43. Tombaugh TN, Hubble AM. The 60 item Boston Naming Test: Norms for cognitively intact adults aged 25 to 88 years. *J Clin Exper Neuropsychol.* 1997;19:922-932.
44. Krupp LB, Elkins LE. Fatigue and decline in cognitive functioning in multiple sclerosis. *Neurology.* 2000;55:934-939.
45. Giavannoni G, Thompson AJ, Miller DH, Thompson EJ. Fatigue is not associated with raised inflammatory markers in multiple sclerosis. *Neurology.* 2001;57:676-681.
46. Krupp LB, Alvarez LA, LaRocca NG, Scheinberg L. Fatigue in multiple sclerosis. *Arch Neurol.* 1988;45:435-437.
47. Monks J. Experiencing symptoms in chronic illness: fatigue in multiple sclerosis. *Int Disabil Studies.* 1989;11:78-83.
48. Leo GJ, Rao SM, Bernardin L. Sleep disturbances in multiple sclerosis. *Neurology.* 1991;41(Suppl 1):320.
49. Saunders J, Whitham R, Schaumann B. Sleep disturbance, fatigue and depression in multiple sclerosis. *Neurology.* 1991;41(Suppl 1):320.
50. Foley FW, Dince WM, Bedell JR, et al. Psychoremediation of communication skills for cognitively impaired persons with multiple sclerosis. *J Neurol Rehabil.* 1994;8:165-176.
51. Hinchcliffe FJ, Murdoch BE, Theodoros DG. Treatment of language disorders in multiple sclerosis. In Murdoch BE, Theodoros DG (Eds). *Speech and Language Disorders in Multiple Sclerosis.* London: Whurr Publishers, 2000.
52. Krupp LB. Measuring MS-related fatigue. *Int J MS Care.* 2002;4(suppl):1-4.
53. Newell S, Sanson-Fisher RW, Girgis A, Bonaventura A. How well do medical oncologists' perceptions reflect their patients' reported physical and psychosocial problems? Data from a survey of five oncologists. *Cancer.* 1998;83:1640-1651.
54. Hall Lord ML, Larsson G, Steen B. Pain and distress among elderly intensive care unit patients: comparison of patients' experiences and nurses' assessments. *Heart Lung.* 1998;27:123-132.
55. DeBoer MF, McCormick LK, Pruyt JFA, et al. Physical and psychosocial correlates of head and neck cancer: A review of the literature. *Otolaryngol Head Neck Surg.* 1999. 120:427-436.