Digital registry-based solution for screening and management of fatigue and cognitive problems in multiple sclerosis

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Abstract

Background: Digital patient registries are actively used in the monitoring of long-term diseases. The potential of the registries in the management of symptoms is underutilized.

Objective: The present paper reports the Finnish registry-based procedure to screen and manage cognitive symptoms and fatigue in multiple sclerosis (MS). The data collected during the first two years is presented.

Methods: The Symbol Digit Modalities Test (SDMT), the Multiple Sclerosis Neuropsychological Questionnaire (MSNQ), and the Fatigue Scale for Motor and Cognitive Functions (FSMC) were implemented into the Finnish MS registry to screen symptoms related to cognition and fatigue. For self-management purposes, feedback reports based on the results on the MSNQ and the FSMC were created. To assess patient-perceived disease severity, disability, and quality of life (QoL), the Patient-Reported Expanded Disability Status Scale (PREDSS), the Visual Analogue Scales (VAS), and the Euro Quality of Life – 5 Dimension (EQ-5D) were implemented into the registry.

Results: At the end of 2020, Finnish procedure to screen and manage patient-perceived concerns related to cognition and fatigue together with self-assessment of disease status, symptoms, and QoL annually was introduced. By the beginning of 2023, 134 patients have been assessed with the SDMT. 329 patients have filled out the FSMC and 172 patients the MSNQ at least once and have received the corresponding feedback reports. The mean SDMT score is 49.6, MSNQ score 35.3, total FSMC score 63.0, and sub-score for motor and cognitive fatigue 31.6 and 31.5, respectively.

Conclusions: The Finnish MS registry offers a digital platform for systematic screening and self-management of fatigue and cognitive problems in MS. Patient registries should be better recognized as e-Health solutions.

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Abstract

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Conclusions: The Finnish MS registry offers a digital platform for systematic screening and self-management of fatigue and cognitive problems in MS. Patient registries should be better recognized as e-Health solutions.

Key words: Multiple Sclerosis; Electronic Health Records; Digital Health; Patient-generated data; Cognition; Fatigue

Introduction

Multiple Sclerosis (MS) registries are in active use in many European countries [1], and a need to develop registry-based data collection is recognized worldwide [2]. Registries help with patients´ follow-up and care [3, 4]. There is a need to increase patient involvement and collection of patient-generated data. Tools to identify and manage the wide range of patient-perceived MS-related concerns are needed. Moreover, there is a special need for early recognition of symptoms and factors which affect productivity and quality of life (QoL).

The Finnish MS registry was launched in 2014 to enable digital treatment monitoring, systematic follow-up of incidence and prevalence, as well as course of the disease [5]. The registry or parts of it is used in 17 out of 21 of Finland’s wellbeing services counties including all five university hospitals. A patient interface for patient-reported outcomes (PRO) was created in 2017 allowing patients to contribute health data on their symptoms, quality of life and overall wellbeing to inform the health care professionals (HCP) and to support patient centered treatment decisions [6]. The PROs implemented in the patient interface include validated patient-reported outcome measures (PROMs) as well as more informal PRO data.

Fatigue has been presented as the most common symptom of MS with the rate of up to 80 % [7, 8, 9] whereas 50 % of patients with MS have been shown to have cognitive deficits [10]. The negative effects of cognitive problems and fatigue on working ability have been shown in registry-based studies [11, 12]. Self-perceived cognitive problems and fatigue have shown a linear relationship with days in sick leave and decrease in weekly working hours and self-perceived working ability [11]. Furthermore, impaired processing speed as evaluated by the Symbol Digit Modalities Test (SDMT) has been found to be related to decreased work productivity as measured by days is sick leave and total annual income [12]. Cognitive deficits and fatigue as invisible symptoms remain often underdiagnosed and treatment options are considered too late to promote working ability. Because the underlying mechanisms of fatigue are multifaceted and no clear definition for the symptom exists, the assessment is particularly challenging and relies heavily on patient report [7]. The fact that fatigue and cognitive concerns have been reported to be confounded with depression and problems with mood further complicates the assessment of the symptoms [7]. At the same time, the detrimental effects of fatigue and cognitive concerns on employment call for early diagnostics and treatment.

In 2020, a Finnish initiative called Invisible symptoms in MS was presented to meet the need to consider cognitive symptoms and fatigue systematically and in a cost-effective way already at the early phases of the disease. The primary aims of the initiative were to promote early and holistic evaluation and treatment of MS, and to offer patients tools to evaluate and manage fatigue and cognitive problems by themselves. The objective of this paper is to describe the procedure to screen and manage fatigue and cognitive problems by using the Finnish MS registry. Furthermore, descriptive statistics on the data collected into the registry during the first two years after the implementation of the procedure are reported.

Methods

Study Context

The Finnish MS registry is a browser-based registry for public health care organizations [5]. The software service is provided by StellarQ (stellarq.fi/en). The use of the registry is voluntary, and each wellbeing services county has decided individually whether to acquire it. At present, 17/21 counties use the registry with data on over 12 500 MS patients. This is estimated to cover approximately 90 % of all MS patients in Finland [6]. All patients registered in the clinician-based registry can use the patient interface, called MyMS, which can be accessed by the national Finnish electronic authorization. 1201 patients with MS were reported to use MyMS at the beginning of 2023 [6].

MyMS has existed since 2017 with the possibility to record background and lifestyle factors, suspected relapses, medications, need of assistance and social support, rehabilitation, and other diseases. Furthermore, three self-rating questionnaires, the Fatigue Severity Scale (FSS), the Multiple Sclerosis Impact Scale-29 (MSIS-29), and the 15D quality of life scale have been available for users to assess their conditions [6].

Registry-based screening of fatigue and cognitive problems

The SDMT [13] was implemented into the clinician-based MS registry to screen for cognitive impairment. The use of the test is based on the license from the test publisher, Western Psychological Services. The SDMT is a test of cognitive processing speed. It has been validated in Finnish [14]. It consists of a sheet with nine symbols presented in pseudo-randomized lines. Each symbol is paired with a digit 1-9 in a key at the top of the sheet. The patient is asked to pair orally, in order, as many of the symbols to the corresponding digits as they can in 90 seconds. MS nurses in the clinics were educated to record the test performance digit by digit to the MS registry. In addition to virtual training, they were provided with written instructions with illustrations to perform the test adequately.

To assess self-perceived cognitive symptoms and fatigue, the validated Finnish versions of the Multiple Sclerosis Neuropsychological Questionnaire (MSNQ) [14, 15], and the Fatigue Scale for Motor and Cognitive Functions (FSMC) [14, 16] were implemented into the MyMS with permissions and licenses from the authors of the questionnaires. The MSNQ consists of 15 questions assessing cognitive problems with the scale ranging from 0 (never) to 4 (frequently). In addition to the total score (range 0-60), post-hoc mean sub scores for memory and learning (questions 4-9; range 0-4), attention (questions 1, 2, and 11; range 0-4), and other cognitive functions (questions 3, 10, and 12-15; range 0-4) were recorded. The FSMC consists of 20 arguments related to motor and cognitive aspects of fatigue with the scale ranging from 1 (totally disagree) to 5 (totally agree). The total score (range 20-100), and separate scores for cognitive and motor fatigue (range 10-50) were recorded. Feedback reports based on the patient's answers in the MSNQ and the FSMC were developed.

Self-evaluation of the disease severity was conducted by using the patient-reported expanded disability status scale (PREDSS) [17], neurological symptoms with Visual Analogue Scales (VAS), and quality of life with the Euro Quality-5 Dimensions (EQ-5D) [18]. Each of these scales were implemented into MyMS. The VAS on mood was used to control for the effects of mood on self-perceived fatigue and cognitive symptoms. The questionnaires are scored according to the standardized procedures of the instruments.

MS patients were familiarized with MyMS by the MS nurses in the hospital clinics. Educational material on how to introduce MyMS to the patients and how to perform the SDMT was created for the nurses. In addition to the MS nurses, Finnish MS associations informed patients on the possibilities MyMS offers to follow their disease and invisible symptoms in particular.

Ethical approval and data analyses

According to Finnish legislation, the approval of an ethical committee was not required as the study was a non-interventional registry study in which patients were not contacted. Patients permit the use of the data for research purposes when they log into the registry. All used data was permitted via Finnish Social and Health Data Permit Authority Findata which answers for data permits considering secondary use of data with multiple data sources and registry keepers (findata.fi/en/), permission number THL/2104/14.05.00/2023 findata-rems-2023. Clinical data was extracted from the Finnish MS registry and PRO data from the MyMS. StellarQ is the data processor for all data extracted.

Date imputation as middle of the month or year was used for clinical variables with partial dates. Date imputation was not needed for patient-reported data. Date of the first data entry in the patient interface was considered as index date to calculate age and disease duration. Descriptive statistics for demographics and PRO measures included means, standard deviations, medians, and quartiles for continuous variables, and counts and proportions for categorical variables. In addition, the proportion of missing data was reported.

In correlation analysis each paired sample was derived as the first matching date within 28 days between two PRO assessments. Correlation coefficients and testing were based on Pearson's product moment correlation. For controlling and checking the False Discovery Rate, Benjamini-Hochberg procedure was used as correction for multiple comparisons. P-values under 0.05 after the correction were considered significant. All data analyses were done using RStudio (version 2021.09.1).

Results

Recommendations to screen and manage fatigue and cognitive problems

As a result of the Invisible symptoms initiative, national recommendations for registry-based evaluation of cognitive problems and patient-perceived fatigue along with the patient-perceived disability and QoL were introduced (Figure 1). The Expert Academic Advisory Board for the Finnish MS registry accepted the Invisible symptoms initiative as well as the recommendations.
[Figure 1 about here]

According to the Finnish MS registry user's guidelines, the baseline SDMT is recorded into the clinical MS registry by a MS nurse. SDMT is reassessed annually to observe any change in processing speed. If a significant change (>10% compared to the baseline score or > 4 points) is observed, the patient should be referred to a comprehensive neuropsychological assessment. Furthermore, patients are instructed to fill out the neurological disability and symptoms section of MyMS (Figure 1). This section includes the evaluation of the disability with the PREDSS and symptoms with the VASs. In addition to self-evaluation, patients are offered information on disease severity and each MS-related neurological symptom. After completion of this section, patients are asked to fill out the self-rating questionnaire on cognition, the MSNQ, and on fatigue, the FSMC. After filling out the MSNQ, patients receive structured feedback report on the severity and characteristics of their cognitive symptoms together with basic information, and practical tips (Textbox 1). Similarly, feedback is offered after filling out the FSMC (Textbox 1). The reports are based on standard scoring of the questionnaires [15,16]. The reports include a summary of the severity and characteristics of the symptoms together with practical strategies to overcome problems in daily life. Emphasis is put on the strategies which can be easily adopted into the daily life of the patients.

Textbox 1. Content of the feedback reports based on the MSNQ and the FSMC.

Multiple Sclerosis Neuropsychological Questionnaire (MSNQ)	Fatigue Scale for Motor and Cognitive Functions (FSMC)
Total score and interpretation	Scores and interpretation - Total score - Sub-score for motor fatigue - Sub-score for cognitive fatigue
Basic information on cognitive problems in MS	Basic information on fatigue
Practical tips for the management of cognitive problems - attentional functions - learning and memory - cognitive flexibility, fluency, behavioral regulation	Practical tips for the management of fatigue - sleep - nutrition - distractors - physical and cognitive activity - energy conservation and breaks
Further steps - sources of information - what to do if cognitive problems require further assessment	Further steps - sources of information - what to do if fatigue requires further assessment

Descriptive statistics from the Finnish MS registry

The invisible symptoms procedure is available in 17 out of 21 Finnish wellbeing services counties which use the Finnish MS registry [6]. The introduction of the procedure has been gradual. The present sample (n=803) includes data from five (Southwest Finland, Satakunta, Pirkanmaa, Central Finland, North Savo) counties. The mean age of the patients at the time of first PRO recording was 43.3 years. The median disease duration was 5.5 years, and 82.3% of the patients had relapsing remitting MS. The median EDSS score was 2.5 (Table 1).

Table 1. Demographic and disease-related variables from the clinical MS registry on the patients of the present sample.

Variable	Total population (N = 803)

Age at MS onset (years); mean (SD)	32.9 (9.88) [m[f]: 21 %]
Age at MS diagnosis (years); mean (SD)	35.3 (10.15)
Age at first PRO recording (years); mean (SD)	43.3 (10.63)
Sex (Female); n (%)	631 (78.6 %)
Disease course; n (%)	
RRMS[a], n (%)	661 (82.3 %)
SPMS[b], n (%)	55 (6.8 %)
PPMS[c], n (%)	45 (5.6 %)
UNS[d], n (%)	42 (5.2 %)
Disease duration (years); median [Q1, Q3]	5.5 [1.0, 12.7]
EDSS[e]; median [Q1, Q3]	2.5 [1.5, 3.5] [m[f]: 11 %]
Education (years); mean (SD)	14.1 (2.74) [m[f]: 30 %]
Smoking (Yes); n (%)	98 (12.9 %) [m[f]: 5 %]

[a]relapsing remitting, [b]secondary progressive MS, [c]primary progressive MS, [d]unspecified disease course; [e]Expanded Disability Status Scale; [f]missing data.

Out of the total 803 patients who have recorded any data into MyMS, 349 patients have filled out the PREDSS with the mean score of 2.9, and 297 patients have filled out the EQ-5D with the mean score of 0.8 (range 0-1) (Table 2). 134 patients have been assessed with the SDMT with the mean score of 49.6. The mean VAS scores (range 0-100) on problems related to fatigue, cognition, and mood were 45.2, 34.1, and 25.9, respectively. The mean total FSMC score (range 20-100) was 63.0, and motor and cognitive sub-score 31.6 and 31.5, respectively. The mean total MSNQ score (range 0-60) was 35.3. The mean post-hoc sub-scores on memory and learning, attention, and other cognitive functions were 2.2, 2.4, and 2.0, respectively (range 0-4). When evaluating how well the patients with most used PROMs (PREDSS with 349 and FSMC with 329 patients) represented our MyMS sample (n=803), we observed that women and patients with short disease duration were overrepresented (gender $p<0.01$, disease duration $p<0.001$).

Table 2. Results on the SDMT and the patient-reported measures of disability, quality of life, fatigue, cognition, and mood.

Variable	n	Mean (SD)	Median [Q1, Q3]
Patient-reported EDSS score (PREDSS)	349	2.9 (1.67)	3.0 [2.0, 4.0]
Symbol Digit Modalities Test (SDMT) score	134	49.6 (13.78)	49.0 [40.0, 57.0]
VAS[a] scores, neurological symptoms			
Fatigue	319	45.2 (27.78)	42.0 [20.0, 70.0]
Cognition	295	34.1 (25.96)	30.0 [10.5, 52.0]
Mood	264	25.9 (26.10)	15.0 [6.8, 37.2]
EuroQuality of Life-5D score	297	0.8 (0.19)	0.8 [0.7, 0.9]
FSMC[b] scores			

Total	329	63.0 (22.49)	68.0 [47.0, 80.0]
Motor fatigue	337	31.6 (11.43)	34.0 [24.0, 41.0]
Cognitive fatigue	331	31.5 (11.68)	32.0 [23.0, 41.0]
MSNQ[c] scores			
Total score	172	35.3 (9.39)	35.0 [28.0, 41.2]
Memory and learning	215	2.2 (0.74)	2.3 [1.7, 2.7]
Attention	291	2.4 (0.85)	2.3 [1.8, 3.0]
Verbal, problem solving, and behaviour	199	2.0 (0.64)	2.0 [1.5, 2.3]

PREDSS 0-9 where 0 stands for no disability and 9 for bedridden most of the time; [a]Visual Analogue Scale scores where 0 stands for no problems and 100 for worst possible problems; higher scores refer to better quality of life in EQ-5D (range 0-1) and more severe symptoms/problems in the [b]Fatigue Scale for Motor and Cognitive Functions total score range 20-100, sub-score range 10-50, [c]Multiple Sclerosis Neuropsychological Questionnaire total score range 0-60, sub-scores are means (range 0-4).

The correlation analyses showed significant relationships between disease duration and EDSS [19] as well as PREDSS (Table 3). Disease duration did not have a significant relationship with any of the measures on mood, fatigue, cognition, or QoL. The EDSS correlated significantly with the SDMT and the VAS score on fatigue and cognition, QoL, and measures of FSMC. The PREDSS showed correlations similar to those of the EDSS. Neither the EDSS nor the PREDSS correlated significantly with the measures of the MSNQ. The SDMT did not correlate significantly with the self-reports on mood, fatigue, or cognition. Instead, the correlation between the SDMT and QoL was significant. The VAS scores on fatigue, cognition, and mood correlated consistently with each other, and the EQ-5D. Both the FSMC scores as well as the MSNQ scores showed significant correlations with self-reports on fatigue, cognition, mood, and QoL.

Table 3. Correlation analyses on disease duration, disability, SDMT, PROMs on fatigue, cognition, and depression as well as QoL.

	DDUR	EDSS	PREDSS	SDMT	VAS-F	VAS-C	VAS-M	EQ-5D	FSMC-T	FSMC-M	FSMC-C	MSNQ-T	MSNQ-M	MSN
S[b]	0.29***													
DSS[c]	0.33***	0.81***												
T[d]	-0.01	-0.35**	-0.41*											
F[e]	0.14*	0.40***	0.39***	-0.29										
C[f]	0.05	0.28***	0.29***	-0.28	0.69***									
M[g]	0.01	0.12	0.15*	-0.05	0.49***	0.38***								
D[h]	-0.06	-0.64***	-0.59***	0.56*	-0.55***	-0.35***	0.46***							
C-T[i]	0.05	0.36***	0.38***	-0.24	0.71***	0.63***	0.37***	-0.59***						
C-M[j]	0.09	0.44***	0.47***	-0.24	0.71***	0.56***	0.32***	-0.60***	0.97***					
C-C[k]	0.01	0.27***	0.27***	-0.22	0.66***	0.65***	0.35***	-0.55***	0.97***	0.87***				
Q-T[l]	-0.09	0.12	0.12	-0.61	0.55***	0.60***	0.33***	-0.44***	0.60***	0.50***	0.63***			
Q-M[m]	-0.11	0.10	0.08	-0.24	0.48***	0.51***	0.26**	-0.34***	0.59***	0.49***	0.61***	0.92***		
Q-A[n]	-0.02	0.19*	0.10	-0.18	0.48***	0.63***	0.27***	-0.41***	0.70***	0.58***	0.75***	0.85***	0.71***	
Q-O[o]	-0.09	0.12	0.07	-0.09	0.46***	0.51***	0.33***	-0.40***	0.57***	0.47***	0.60***	0.89***	0.68***	0.72

[a]disease duration, [b]Expanded Disability Status Scale, [c]patient reported EDSS, [d]Symbol Digit Modalities Test, [e]Visual analogue scale - fatigue, [f]Visual analogue scale - cognition, [g]Visual analogue scale - mood, [h]Euro Quality 5- Dimension,

[i] Fatigue Scale for Motor and Cognitive Functions total score, [j] Fatigue Scale for Motor and Cognitive Functions motor score, [k] Fatigue Scale for Motor and Cognitive Functions cognitive score, [l] Multiple Sclerosis Neuropsychological Questionnaire, total score, [m] Multiple Sclerosis Neuropsychological Questionnaire memory score, [n] Multiple Sclerosis Neuropsychological Questionnaire attention score, [o] Multiple Sclerosis Neuropsychological Questionnaire other cognitive functions score; *p<0.05, ** p<0.01, *** p<0.001.

Discussion

The Finnish Invisible symptom initiative presents a unique procedure for registry-based screening and management of fatigue and cognitive concerns. Annual assessment of the SDMT enables healthcare professionals to observe any change in patient's information processing speed. Along with the objective evaluation of cognition with the SDMT, patients are asked to perform self-assessment of cognitive problems with the MSNQ and fatigue symptoms with the FSMC in the patient interface of the registry. For follow-up purposes, patients are instructed to perform self-assessment annually before their neurology appointment. Besides that, they can perform reassessment whenever needed. The procedure is in line with the recommendations presented by Kalb and colleagues [20] for baseline screening and annual follow-up of cognitive performance in MS using the SDMT. The SDMT has been introduced as the most sensitive measure of cognitive performance and processing speed in MS [21]. The Finnish validation of the Brief International Cognitive Assessment in Multiple Sclerosis (BICAMS) showed that the SDMT was the most sensitive measure of the BICAMS also in Finnish patients with MS [14]. In the same study, the MSNQ and the FSMC were shown to be applicable in the self-evaluation of fatigue and cognitive symptoms when the effects of mood state are adequately controlled for. To assess patient perspective, the MSNQ and the FSMC were thus implemented into the patient interface of the Finnish MS registry. The VAS score on mood was used to control the effects of mood on fatigue and cognitive concerns.

The mean SDMT score in the present registry-based sample was higher than that observed in the Finnish validation study with older and more disabled patients [14] but in line with international studies with patients with similar age and EDSS [22-25]. Based on the FSMC [16], the patients of the present sample reported severe overall fatigue and moderate motor and cognitive fatigue. Based on the MSNQ [15], they also perceived at least occasional problems with cognitive functions. The patients of the present sample reported more fatigue and cognitive concerns than the patients in the Finnish validation study [14]. Further, the FSMC scores of the present sample were higher than those in another Finnish study with RRMS patients [9]. It is expected that the present sample is overrepresented with patients with pronounced fatigue and cognitive symptoms because especially those patients have probably been instructed to fill out the questionnaires to get help in the management of the harmful symptoms.

In the present sample, physical disability as measured with either the EDSS or the PREDSS correlated with all the self-reports used except the MSNQ. On the contrary, disease duration did not have a significant relationship with the self-reports showing that invisible symptoms may emerge at any phase of the disease, and quality of life may be compromised already at the early phases of the disease. The SDMT correlated with both the EDSS and the PREDSS. The SDMT did not show a significant relationship with the self-report on depression. On the contrary, self-reports on fatigue and cognitive problems correlated significantly with that on depression. These results are in line with earlier findings that concerns with fatigue, cognition, and mood are interrelated and should all be considered in the screening and search for optimal treatment methods [14,15].

Comprehensive management of invisible symptoms requires effective communication between health care professionals (HCP) and patients [26]. The Finnish invisible symptoms initiative offers a systematic way to approach patient-perceived cognitive problems and fatigue as well as overall disability and QoL. Cognitive performance as well as patient-perceived aspects of the disease including cognitive and fatigue symptoms can be evaluated annually with validated tools and the results are readily available for the patients in the patient interface and for the HCPs in the clinician's interface. According to a European survey published in 2019 [1], only seven out of 19 identified MS registries include patient derived measures. Individualized patient-centered treatment is the gold standard of high-quality care [27, 28]. The 21st Century Steering Group [28] has highlighted the need to further improve communication between the patient and health care professionals to promote patient participation and self-management, as well as to enable access to high-quality information. Systematic self-report is a way to empower patients to take responsibility for their disease and commit to the treatment, and beneficial lifestyle choices [28,29]. As stated by Lakin and colleagues [26] by paring clinical knowledge with an understanding and consideration of the patient perspective, HCPs are equipped to foster patient-centered dialogue that encourages shared decision making and high-quality care. Early interventions targeted to the symptoms affecting employment such as those to cognition and fatigue [11,12] may improve not only QoL but also productivity.

In addition to the possibility to evaluate cognitive symptoms and fatigue, it is important to offer patients practical tools to manage these symptoms in each patient's daily life [10]. In the invisible symptoms initiative, feedback reports based on the patient's answers in the MSNQ and the FSMC were developed. Digital self-management tools could even be developed further by designing online rehabilitation where already existing assessment, feedback, and strategies are combined with individual goal setting and professional counselling. Neuropsychological and cognitive rehabilitation and even computer-based treatments delivered at home have shown positive effects on the management of cognitive symptoms [30, 31]. Especially cost-effective, individualized, and holistic intervention with an input from HCP has been called for [10]. The Finnish initiative concentrated on seeking for strategies to understand, evaluate, and manage cognitive problems and fatigue. The procedure developed can be extended to other invisible symptoms such as those on mood, sexuality, and bladder and bowel functions.

There are several limitations in the present study. The procedure to screen and manage fatigue and cognitive concerns has existed only for two years and is not yet consistently used. Thus, the sample size of the present study is relatively small. It only represents the data from five out of 21 wellbeing services counties which represent approximately 40 % of the whole MS population in Finland. There is an ongoing effort to adopt the procedure to the MS treatment pathway of each county. However, the lack of knowledge on the use of PROMs and the difficulties to interpret and utilize PROM data in often fast-paced clinical decision making have possibly decelerated the use of patient-generated data. Based on the results of the present study, the sample may over-represent patients with fatigue and cognitive concerns. At the same time, this finding seems to certify the need for assessment and management tools for invisible signs such as those on cognition and fatigue.

To conclude, the digital patient interface offers an e-Health platform for patient-generated data and enables patients as well as health care professionals to bring up harmful symptoms. Active use of the PROM data together with that in the clinician-based MS registry offers a systematic way to conduct cost-effective care by engaging and empowering patients to take charge of their disease and commit to the treatment choices.

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Conflicting of interest

PH is an employee of the Finnish Neuro Society and StellarQ. PH has served as an adviser or speaker for Merck, Novartis, and Sanofi.

EL is an employee of Novartis Finland Oy.

MV None.

HK has served as an adviser or speaker for Merck, Biogen, Celgene (BMS), Novartis, Roche, Jansen Cilag, Teva, Sandoz and Sanofi and support for congress participation from Merck.

MN has served as an adviser or speaker for Novartis, Roche, Merck, Sanofi and Teva; and support for congress participation from Novartis, Merck, Roche and Sanofi.

JP None.

MR has received honoraria for lectures, advisory boards, congress visit or for serving as an investigator for clinical trials from Abbvie, Biogen, Merck, Novartis, Roche, Sandoz, Sanofi.

JR None.

M S-H has served as an adviser or speaker for Biogen, Celgene (BMS), Novartis, Roche, Sanofi, and Teva; has received institutional research grants for clinical research from Bayer, Biogen, Merck, Novartis, and Roche; and support for congress participation from Biogen, Celgene (BMS), Novartis, Roche, Sanofi, and Teva.

Abbreviations

BICAMS: Brief International Cognitive Assessment for multiple sclerosis
EQ-5D: Euro Quality of Life – 5 Dimension
FSMC: Fatigue Scale for Motor and Cognitive Functions
FSS: Fatigue Severity Scale
HCP: health care professional
MS: multiple sclerosis
MSIS-29: Multiple Sclerosis Impact Scale -29
MSNQ: Multiple Sclerosis Neuropsychological Questionnaire
PREDSS: Patient Reported Expanded Disability Status Scale
PRO: Patient reported outcome
PROM: Patient reported outcome measure
QoL: Quality of Life
SDMT: Symbol Digit Modalities Test
VAS: Visual Analogue Scale

Data availability

The clinical data presented in the present manuscript was extracted from the Finnish MS registry and PRO data from the MyMS. The Finnish wellbeing services counties are the data owners whereas StellarQ acts as the data processor for all data extracted. The data was processed in Kapseli which is a Findata-provided secure operating environment for the processing of data on individuals.

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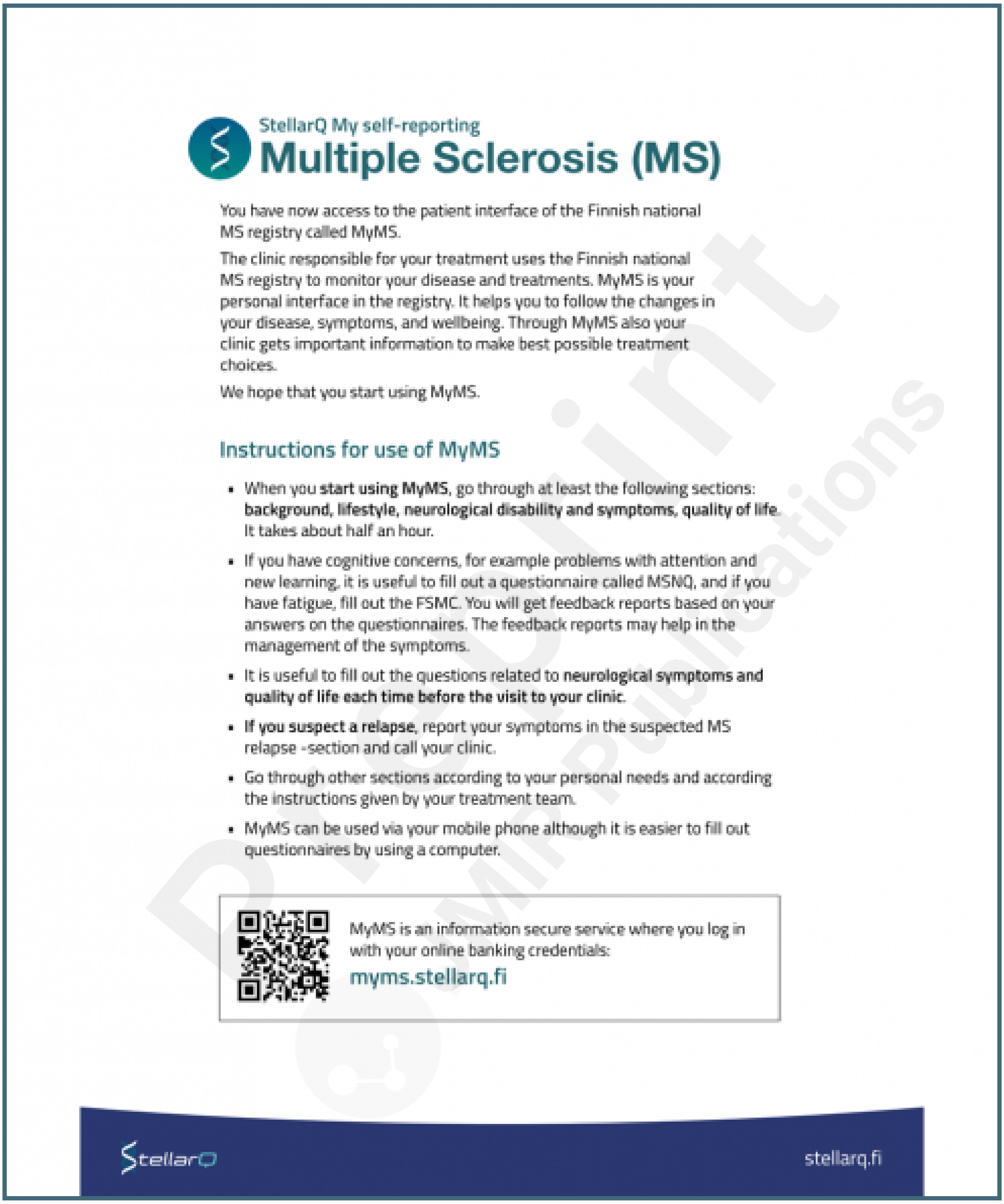
Supplementary Files

Figures

Recommendations and instructions for the use of MyMS.



StellarQ My self-reporting

Multiple Sclerosis (MS)

You have now access to the patient interface of the Finnish national MS registry called MyMS.

The clinic responsible for your treatment uses the Finnish national MS registry to monitor your disease and treatments. MyMS is your personal interface in the registry. It helps you to follow the changes in your disease, symptoms, and wellbeing. Through MyMS also your clinic gets important information to make best possible treatment choices.

We hope that you start using MyMS.

Instructions for use of MyMS

- When you **start using MyMS**, go through at least the following sections: **background, lifestyle, neurological disability and symptoms, quality of life**. It takes about half an hour.
- If you have cognitive concerns, for example problems with attention and new learning, it is useful to fill out a questionnaire called MSNQ, and if you have fatigue, fill out the FSMC. You will get feedback reports based on your answers on the questionnaires. The feedback reports may help in the management of the symptoms.
- It is useful to fill out the questions related to **neurological symptoms and quality of life each time before the visit to your clinic**.
- **If you suspect a relapse**, report your symptoms in the suspected MS relapse -section and call your clinic.
- Go through other sections according to your personal needs and according the instructions given by your treatment team.
- MyMS can be used via your mobile phone although it is easier to fill out questionnaires by using a computer.

MyMS is an information secure service where you log in with your online banking credentials:

myms.stellarq.fi

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