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ORIGINAL COMMUNICATION

Factors influencing patient satisfaction with the first diagnostic consultation in multiple sclerosis: a Swiss Multiple Sclerosis Registry (SMSR) study

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Abstract

Background Patient satisfaction is predictive of adherence, malpractice litigation and doctor-switching.

Objective To investigate which factors of the first diagnostic consultation (FDC) influence patient satisfaction and which topics persons with multiple sclerosis (PwMS) thought were missing.

Methods Using retrospective patient-reported data of the Swiss Multiple Sclerosis Registry from PwMS with relapsing disease onset, we fitted ordered logistic regression models on satisfaction with FDC, with socio-demographic and FDC features as explanatory factors.

Results 386 PwMS diagnosed after 1995 were included. Good satisfaction with the FDC was associated with a conversation more than 20 min [multivariable odds ratio, 95% confidence interval 3.9 (2.42; 6.27)], covering many topics [1.35 (1.19; 1.54) per additional topic], the presence of a significant others [1.74 (1.03; 2.94)], and shared decision making [3.39 (1.74; 6.59)]. Not receiving a specific diagnosis was main driver for low satisfaction [0.29 (0.15; 0.55)]. Main missing topics concerned long-term consequences (reported by 6.7%), psychological aspects (6.2%) and how to obtain support and further information (5.2%).

Conclusions A conversation of more than 20 min covering many MS relevant topics, a clear communication of the diagnosis, the presence of a close relative or significant other, as well as shared decision making enhanced patient satisfaction with the FDC. ClinicalTrials.gov Identifier: NCT02980640

Keywords First diagnostic consultation · Multiple sclerosis · Registries · Patient satisfaction · Diagnosis communication · Shared decision making

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Them members of For the Swiss Multiple Sclerosis Registry (SMSR) are listed in Acknowledgements.

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Introduction

Patient satisfaction is crucial in the care of patients, with low patient satisfaction being predictive of poor therapy adherence, doctor switching and malpractice litigation [1–4].The Picker Institute (https://www.picker.org), a non-profit organization that makes patients' views count in healthcare, identified eight characteristics as the most important indicators of quality and safety of care from the patients perspective: (1) respect for the patient's values, preferences, and needs; (2) coordinated and integrated care; (3) high-quality information for patients and their families; (4) physical comfort; (5) emotional support; (6) involvement of family members and friends; (7) continuity of care; and (8) access to care [5]. Successfully addressing these dimensions requires clinicians and patients to cooperate in order to produce the best possible outcomes, a process called "shared decision making". This is especially relevant if more than one reasonable path forward exists, including the option of doing nothing when appropriate [6]. To understand the specific factors in shared decision making leading to an optimal patient satisfaction is essential for patient-centered care.

Persons with MS (PwMS) usually need long-term treatment over decades and an open and constant dialogue with the neurologist is, therefore, indispensable. Shared decision making is an already established practice in the care of PwMS, also because usually several therapeutic options are available [7]. However, choosing the most suitable therapeutic option is often challenging. The reasons for this difficulty are manifold and result mainly from difficulties in predicting the long-term course of the disease that is highly variable amongst patients, a limited ability to predict efficacy, safety and tolerability of specific drugs for individual patients, variability in patient preferences for beneficial outcomes and harms of treatment, as well as drug-specific differences in adverse effect profiles.

The first diagnostic consultation (FDC), during which the MS diagnosis is communicated, is a crucial event that is reported as powerfully evocative and unforgettable by PwMS [8]. It is common that both patients and their partners demonstrate high levels of anxiety and distress during and right after diagnosis [9]. Moreover, it has been reported that negatively experienced FDC might lead to non-adherence up to the complete refusal of neurological care and medication [8, 10]. However, a small number of studies have investigated optimal circumstances of an FDC. For example, several studies found that the FDC should be performed in a suitable setting leaving enough time for discussion, the diagnosis should be communicated early and unambiguously, and the information of the FDC should be tailored to the needs of PwMS possibly using appropriate information and decision support aids [11, 12]. This results in a better knowledge on MS, a significant reduction in uncertainty and decrease of distress, facilitated decision making on disease modifying treatments (DMTs), and finally increased patient satisfaction [10–16].

The aim of the present study was to further investigate factors of the FDC that positively influence patient satisfaction, with the aim to improve the FDC and ultimately also care for PwMS. Thereby, our study complements prior work by relying on comprehensive data and self-report of PwMS about their FDC experience. Moreover, our study draws from an extensive, well-documented database, the Swiss Multiple Sclerosis Registry (SMSR), which is a nationwide, patient-centered cohort currently including data from 2049 participants by June 2019 [17–19].

Materials and methods

The Swiss Multiple Sclerosis Registry (SMSR)

The SMSR is a nationwide patient-centered survey study, entirely funded by the Swiss MS Society. Any adult (≥ 18 years old) with CIS or definite MS who lives or receives care in Switzerland is eligible and the correct diagnosis is confirmed by a treating physician. Participants complete a baseline assessment online or on paper and from there on fill in a follow-up questionnaire every six months [18]. Furthermore, additional questionnaires addressing specific topics can be added at any follow-up. The SMSR started in June 2016 and has recruited more than 2049 participants at 1 June 2019. The SMSR was approved by the Cantonal Ethics Committee Zurich (Study number PB-2016-00894), has been performed in accordance with the ethical standards laid down in the 1964 Declaration of Helsinki and its later amendments, and every patient has signed an informed consent prior to study entry [17, 18]. The ClinicalTrials.gov Identifier is NCT02980640.

First diagnostic consultation (FDC) survey

We added a specific survey addressing the FDC to the first regular 6-month follow-up questionnaire. Because we a priori hypothesized that the availability and number of disease-modifying treatment options may be a strong exogenous influence on the FDC, we restricted our analysis to participants who were diagnosed with CIS or MS on or after 1 January 1996, that is, after the approval of the first DMT (Betaferon/Betaseron®) for MS in Switzerland. PwMS with primary progressive MS (PPMS) were excluded because they were not eligible for DMT up to 2018. Along the same lines, we performed time-stratified analyses using the

introduction of novel DMT types as milestones to separate calendar periods (see below).

The FDC-survey contained 14 questions covering the formal setting of the FDC (place, participants, duration) as well as the communication of diagnosis, discussed topics, presentation of DMTs and the process treatment decisions. The satisfaction of the participants with the FDC was assessed on a scale from 1 to 5 ranging from very unsatisfied (= 1) to very satisfied (= 5).

Statistical analysis

The analysis was performed using R, version 3.4.0 (R Core Team 2017) [20]. Only patients with available information on FDC satisfaction were included in the analysis.

To investigate drivers of FDC satisfaction, an ordered logistic regression model was fitted with the FDC satisfaction as outcome variable and various sociodemographic factors, as well as FDC features as explanatory factors. To enhance the interpretability of the model, satisfaction was further categorized into unsatisfied (levels 1–2), neutral (level 3), and satisfied (levels 4–5).

Fixed factors were sex, age-at-onset (< 20/21–40/above 40), time period of diagnosis (1996–2004/2005–2010/2011–2018), the duration of FDC (less than 10 min/10–20 min/20–30 min/more than 30 min or more consultations), the number of discussed topics (range 0–9), and who decided on DMT (only the neurologist/shared decision/only the patient). To consider the main changes in the DMT array, the diagnosis period was further stratified to reflect the main changes in the DMT array as follows: the first available drugs since 1996, the approval of natalizumab in 2005 and all oral drugs as well as alemtuzumab and ocrelizumab after 2011. Potential additional factors were education level (low or medium/high), the presence of older relatives already with an MS diagnosis (no/yes), the time from the first contact with a physician's office due to the first symptoms to the actual visit (within 1 month/more than 1 month), the time from the actual visit to the diagnosis (within 6 months, more than 6 months), FDC setting (hospital outpatient/hospital in-patient/private practice), whether the partner/a close relative/a significant other was present at the FDC, the clarity of the diagnosis according to the patient (yes/no), MS type at the FDC, how many DMTs were discussed/presented, and the number of first symptoms (out of a list of twenty symptoms, see [19, 21]. Variable selection on the potential factors was based on Akaike's Information Criterion (AIC) [22]. The multivariate imputation by chained equations (MICE) algorithm was used to impute missing confounders [19]. Goodness-of-fit of the regression model was assessed by means of the Hosmer–Lemeshow test and the p value did not reach statistical significance < 0.05 indicating that there was no evidence for a lack of fit.

Results

Study population

The study included 386 participants that completed the FDC-questionnaire and follow-up 6-month survey until July 2018, were diagnosed after 1995, had MS or CIS at FDC and gave a complete information on FDC satisfaction (Fig. 1). The characteristics of the study population are illustrated in Table 1. 75% of the participants were women, with a median age of 46 years at time of survey completion, and 84% of

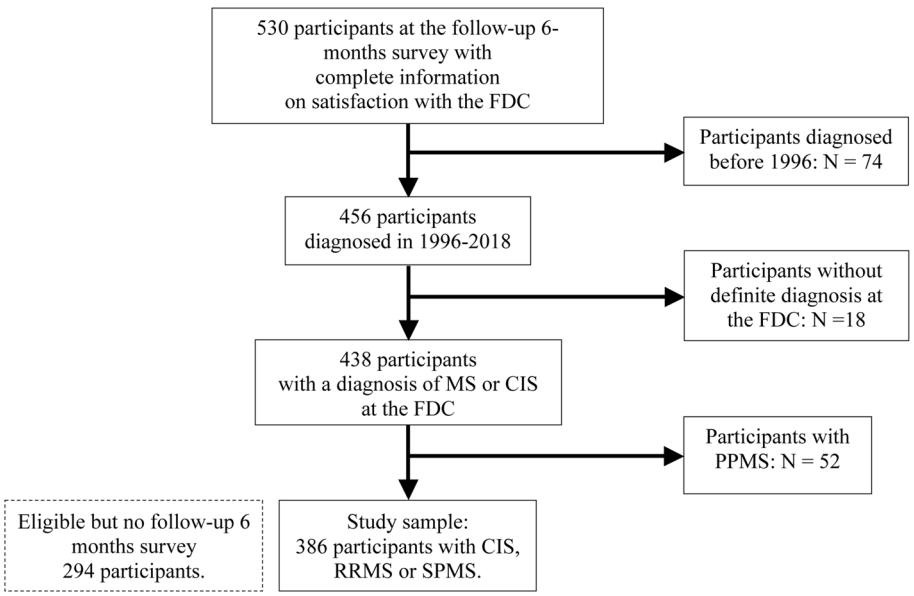

Fig. 1 Flowchart of the sample selection. *FDC* first diagnostic consultation, *n* number, *MD* medical doctor, *CIS* clinically isolated syndrome, *RRMS* relapsing–remitting multiple sclerosis, *SPMS* secondary progressive multiple sclerosis, *PPMS* primary progressive multiple sclerosis, *DMT* disease-modifying treatment

Table 1 Demographics of the study sample

Variable	Levels	Study sample	Eligible participants without a follow-up 6 months survey
Number of participants		386	294
Sex	Female	292 (75.6%)	220 (74.8%)
Age	Median (IQR)	46 (38;5 3)	43 (34; 52)
Years since diagnosis	Median (IQR)	8 (3; 14)	6 (3:12)
MS type at baseline assessment	CIS	13 (3.4%)	9 (3.1%)
	RRMS	314 (81.3%)	238 (81%)
	SPMS	59 (15.3%)	34 (11.6%)
EDSS proxy at baseline	EDSS 0–3.5	323 (83.7%)	245 (83.3%)
	EDSS 4–6.5	42 (10.9%)	35 (11.9%)
	EDSS > = 7	20 (5.2%)	10 (3.4%)
	NA	1 (0.3%)	4 (1.4%)

IQR interquartile range (25–75% quantiles), *CIS* clinically isolated syndrome, *RRMS* relapsing–remitting multiple sclerosis, *SPMS* secondary progressive multiple sclerosis, *EDSS* Kurtzke's Expanded Disability Status scale

them had an EDSS below 4. In total, 294 potentially eligible SMSR participants did not complete the follow-up 6 months survey and could, therefore, not be included in the study population (Fig. 1, dashed box). However, these participants did not differ substantially in relevant aspect from the study sample (Table 1, second column).

Which FDC features affect satisfaction?

Of the 386 participants, 205 (53%) were either satisfied or very satisfied with the FDC, 94 (24%) were neutral, and 87 (23%) were either unsatisfied or very unsatisfied with the FDC.

Table 2 illustrates the main features of the FDC and the clinical information of the participants, stratified by satisfaction levels.

Unsatisfied patients were more frequently between 20 and 40 years old at onset (71% of unsatisfied vs 62% of satisfied), were more often women (83% vs 72%), or had an unspecified MS type (25% vs 9%). With regard to characteristics of their FDC, their interaction with the physician was more often of short duration below 10 min (36% vs 7%), with a perceived unclear diagnosis (36% vs 5%), all decisions on initiation timing and type of DMT being taken by the neurologist (30% vs 7%) or not to have been recommended a DMT at all (32% vs 12%).

Those patients who were satisfied were more likely to be older than 40 at onset (28% satisfied, 17% unsatisfied), to be male (28% vs 18%), to have been diagnosed in or after 2011 (49% vs 33%), to have a shorter diagnostic process (time contact-to-visit within 1 month 71% vs 62%, time visit-to-diagnosis within 6 months 82% vs 69%), or to have an older relative with an MS diagnosis (12% vs 7%). They were also more likely to have had a longer FDC duration (for 20–30 min 22% satisfied vs 12%, for more than 30 min 40% vs 12%), to have a family member or a significant other present at the FDC (40% vs 22%), to have received a clear diagnosis (95% vs 63%), to have addressed more topics at the FDC (median 4 topics vs 1), to have shared the decision on DMT with their neurologist (74% vs 38%), and to have been proposed at least 2 DMTs (69% vs 32%). Of note, there were no topics discussed during the FDC that were associated with a negative impact on satisfaction (Table 2).

The ordered logistic regression model did confirm several of the above observations (Fig. 2). A duration of the FDC longer than 20 min, a more recent year of diagnosis, the number of discussed topics, the presence of a family member/significant other, and a shared decision on DMT were all associated with more satisfaction. To receive an unclear diagnosis was instead associated with low patient satisfaction with the FDC.

Which FDC features were missing?

The participants were asked in an open question which topics they believed were missing at the FDC. In total, 104 of 386 (26.09%) persons mentioned at least 1 topic that was not covered by the FDC. The specific answers ordered by frequency of reporting are listed in Table 3.

Of note, the most frequently voiced discontent with the FDC (8.5%) was that patients would have liked to receive more detailed information during the FDC.

The five most frequently mentioned missing topics concerned long-term consequences of MS, psychological aspects, information about where and how to obtain support, as well as a wish for further information regarding therapies and MS prognosis.

Table 2 Demographics and FDC features, by satisfaction level with the FDC

Factor	Levels	FDC satisfaction level		
		Very unsatisfied/unsatisfied	Neutral	Satisfied/very satisfied
Number of participants	*N*	87 (23%)	94 (24%)	205 (53%)
Age at onset	5–20 years old	5 (5.7%)	7 (7.4%)	11 (5.4%)
	21–40 years old	62 (71.3%)	57 (60.6%)	126 (61.5%)
	41–70 years old	15 (17.2%)	28 (29.8%)	58 (28.3%)
	NA	5 (5.7%)	2 (2.1%)	10 (4.9%)
Sex	Female	72 (82.8%)	72 (76.6%)	148 (72.2%)
Diagnosis period	1996–2004	30 (34.5%)	35 (37.2%)	54 (26.3%)
	2005–2010	28 (32.2%)	23 (24.5%)	50 (24.4%)
	2011–2018	29 (33.3%)	36 (38.3%)	101 (49.3%)
Time from first symptoms to first contact with a physician's office	Within 1 month	54 (62.1%)	68 (72.3%)	146 (71.2%)
	More than 1 month	32 (36.8%)	23 (24.5%)	54 (26.3%)
Time from first contact with a physician's office to the CIS/MS diagnosis	Within 6 months	60 (69%)	70 (74.5%)	168 (82%)
	More than 6 months	27 (31%)	24 (25.5%)	36 (17.6%)
MS in older relatives	No	76 (87.4%)	87 (92.6%)	167 (81.5%)
	Yes	6 (6.9%)	4 (4.3%)	25 (12.2%)
Education level	Medium/low	40 (46%)	38 (40.4%)	90 (43.9%)
	High	43 (49.4%)	50 (53.2%)	104 (50.7%)
	NA	4 (4.6%)	6 (6.4%)	11 (5.4%)
Number of first symptoms	Median (IQR)	3 (1; 5)	3 (2; 5)	3 (1; 5)
Setting of the FDC	Hospital-inpatient	21 (24.1%)	21 (22.3%)	42 (20.5%)
	Hospital-outpatient	22 (25.3%)	30 (31.9%)	60 (29.3%)
	Private practice-outpatient	40 (46%)	43 (45.7%)	100 (48.8%)
	Other	3 (3.4%)	–	3 (1.5%)
	NA	1 (1.1%)	–	–
FDC duration	0–10 min	31 (35.6%)	19 (20.2%)	15 (7.3%)
	10–20 min	29 (33.3%)	23 (24.5%)	47 (22.9%)
	20–30 min	10 (11.5%)	16 (17%)	45 (22%)
	More than 30 min	10 (11.5%)	25 (26.6%)	82 (40%)
	NA	7 (8%)	11 (11.7%)	16 (7.8%)
Who was present at the FDC	One MD	76 (87.4%)	78 (83%)	170 (82.9%)
	More than one MD	11 (12.6%)	14 (14.9%)	32 (15.6%)
	MS nurse	1 (1.1%)	7 (7.4%)	5 (2.4%)
	Nurse	–	2 (2.1%)	4 (2%)
	Partner	12 (13.8%)	22 (23.4%)	54 (26.3%)
	Children	–	1 (1.1%)	3 (1.5%)
	Parent/sibling	5 (5.7%)	8 (8.5%)	25 (12.2%)
	Other	7 (8%)	9 (9.6%)	32 (15.6%)
MS type diagnosed at the FDC	CIS	7 (8%)	6 (6.4%)	21 (10.2%)
	RRMS	50 (62.5%)	61 (69.3%)	144 (78.3%)
	SPMS	5 (6.2%)	5 (5.7%)	11 (6%)
	Not further specified	20 (25%)	18 (20.5%)	17 (9.2%)
	Unknown	5 (6.3%)	4 (4.5%)	12 (6.5%)
Was the diagnosis received clear?	Yes	55 (63.2%)	78 (83%)	194 (94.6%)
	No	31 (35.6%)	15 (16%)	11 (5.4%)
	NA	1 (1.1%)	1 (1.1%)	–

Table 2 (continued)

Factor	Levels	FDC satisfaction level		
		Very unsatisfied/unsatisfied	Neutral	Satisfied/very satisfied
Topics introduced/discussed at the FDC	What MS is	40 (46.5%)	59 (62.8%)	159 (77.9%)
	Cause of MS	10 (11.6%)	19 (20.2%)	84 (41.2%)
	Hereditability of MS	17 (19.8%)	24 (25.5%)	91 (44.6%)
	Future course	24 (27.9%)	38 (40.4%)	138 (67.6%)
	Emotional handling	6 (7%)	7 (7.4%)	39 (19.1%)
	Therapies	43 (50%)	59 (62.8%)	162 (79.4%)
	Life consequences (e.g. family planning)	5 (5.8%)	14 (14.9%)	48 (23.5%)
	Job consequences	9 (10.5%)	13 (13.8%)	58 (28.4%)
	Leisure time and sport	5 (5.8%)	10 (10.6%)	44 (21.6%)
	Other	12 (14%)	7 (7.4%)	8 (3.9%)
	Total number of topics, median (IQR)	1 (1; 2)	2 (1; 4)	4 (2; 6)
Number of DMT suggested by the neurologist at the FDC	No	28 (32.2%)	14 (14.9%)	25 (12.2%)
	1 DMT	26 (29.9%)	25 (26.6%)	37 (18%)
	At least 2 DMTs	28 (32.2%)	50 (53.2%)	142 (69.3%)
	NA	5 (5.7%)	5 (5.3%)	1 (0.5%)
Who decided on DMT	Doctor decided all	26 (29.9%)	15 (16%)	15 (7.3%)
	Shared decision	33 (37.9%)	47 (50%)	151 (73.7%)
	Own decision	16 (18.4%)	26 (27.7%)	33 (16.1%)
	NA	12 (13.8%)	6 (6.4%)	6 (2.9%)

The number and percentage of patients are illustrated except for "number of first symptoms" and "total number of topics" displaying the IQR (interquartile range 25–75% quantiles)

NA not available, *FDC* first diagnostic consultation, *MD* medical doctor, *CIS* clinically isolated syndrome, *RRMS* relapsing–remitting multiple sclerosis, *SPMS* secondary progressive multiple sclerosis, *DMT* disease-modifying treatment

Discussion

Using comprehensive, cross-sectional questionnaire data from 386 participants of the Swiss MS Registry, we analyzed factors influencing patient satisfaction with the FDC. Our analyses show that multiple alterable and non-alterable factors influence patient satisfaction with the FDC (Table 2). Specifically, the multivariable analysis indicates that high patient satisfaction with the FDC results from: (1) the duration of the first diagnostic consultation being longer than 20 min, (2) a high number of discussed topics, (3) the presence of a close relative or a significant other at the FDC, and (4) shared decision making as alterable factors. Regarding non-alterable factors, the FDC taking place after 2011 was also associated with greater satisfaction. A major factor for low patient satisfaction with the FDC was to receive an unclear diagnosis as well as the time period of diagnosis.

Several of those findings fall in line with previous studies. In particular, our observation that receiving an unclear diagnosis and an unspecified MS type at the FDC were associated with low patient satisfaction corroborates earlier results from Papathanasopoulos and co-workers, who found that uncertainty with regard to diagnosis, had a substantial effect on patient satisfaction. This stands in line with the clearly expressed preference amongst most patients for an unambiguous disclosure of the diagnosis [13]. Moreover, other studies observed that patients with a definite diagnosis reported a significant decrease in uncertainty, distress over physical symptoms and anxiety [14]. Along those lines, the diagnostic workup should be performed quickly and diagnosis should be communicated clearly and as early as possible [10].

Our study further indicates that patients prefer to receive as much information as possible about various aspects of the disease. In our multivariable regression, the number of topics covered was strongly associated with greater FDC satisfaction. This finding concurs with other studies showing that information improves patients' knowledge of their condition and satisfaction with the diagnosis communication [10].

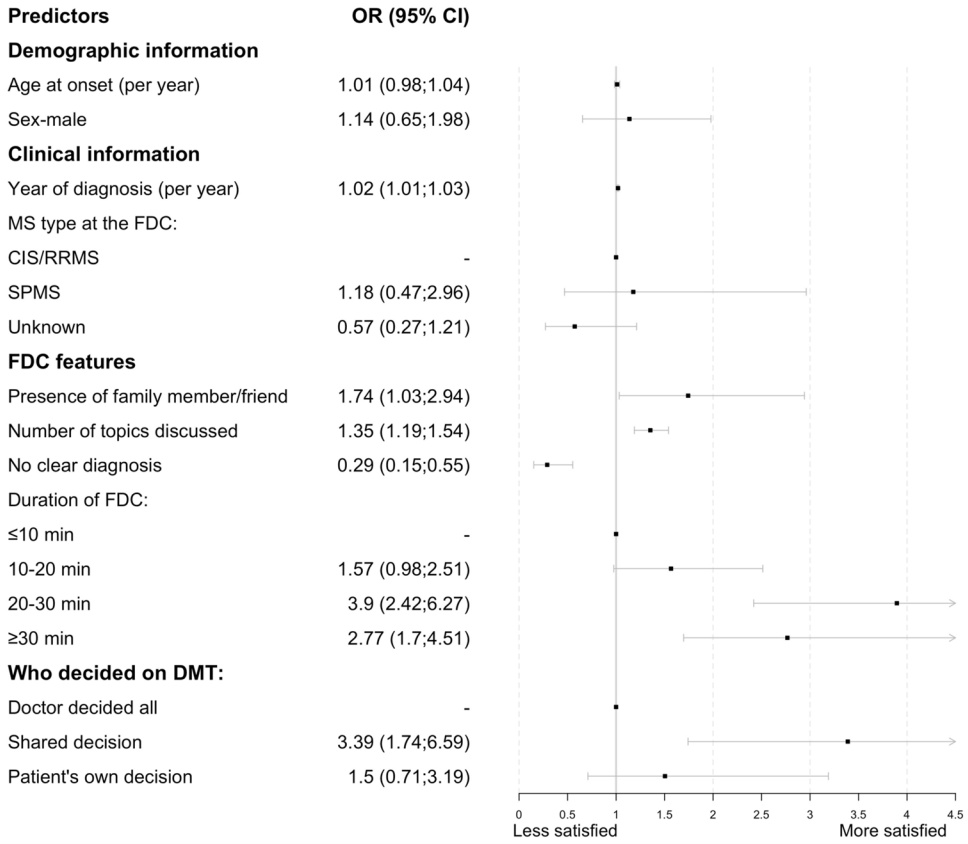

Fig. 2 Model on satisfaction with the FDC. *FDC* first diagnostic consultation, *CIS* clinically isolated syndrome, *RRMS* relapsing–remitting multiple sclerosis, *SPMS* secondary progressive multiple sclerosis, *DMT* disease-modifying treatment

Table 3 Missing topics at the FDC

Topic	*n* (%) of 368 participants
More detailed information in general	33 (8.5%)
Long-term consequences	26 (6.7%)
Psychological aspect of MS	24 (6.2%)
Whom they should ask help to/counseling options	20 (5.2%)
MS therapies	26 (6.7%)
Prognosis	16 (4.1%)
What MS is	14 (3.6%)
MS forms	11 (2.8%)
Everything was missing	10 (2.6%)
Job consequences	8 (2.1%)
Family consequences ($n=6$)	6 (2.1%)
Alternative medicines ($n=5$)	5 (2.1%)
Physiotherapy ($n=5$)	5 (2.1%)

FDC first diagnostic consultation, *n* number

Interestingly, there were no specific topics whose discussion during the FDC had a negative impact on patient satisfaction (Table 2), which is in line with previous studies demonstrating that information provision did not affect anxiety symptoms [10]. Our study also provides insights into additional topics PwMS wish to be covered during the FDC, such as life consequences, psychosocial aspects, or counseling options, as well as receiving more detailed information in general and on therapeutic options in specific (Table 3).

Informing the patient about various aspects of the disease is an integral element of shared decision making and an important contributor to high patient satisfaction with the FDC. In contrast, paternalistic decision making, i.e. when all decisions about DMT initiation are taken by the neurologist, was clearly associated with reduced FDC satisfaction. The advantage of shared decision making with regard to patient satisfaction and adherence to treatments is well known in MS and other diseases, particularly in situations where more than one reasonable path forward exists, including the option of taking no medication when appropriate [5, 6, 23]. Our data further support the already ubiquitously performed strategy to engage PwMS in their disease management and to make treatment decisions jointly between the physician and patient, particularly early in the pathway [24].

Interestingly, the presence of a family member or a significant other at the FDC was also associated with a high patient satisfaction. This might be due to social and emotional support in the process of handling such a crucial moment in the patient's life [8]. In addition, due to emotional distress many patients remember as little as a fifth of the information discussed and immediately forget 40-80% of the content after doctor visits [25, 26]. Family

members and proxies being present during the FDC may also support information processing. Moreover, having a relative diagnosed with MS (not necessarily being present at the FDC) also had a positive, albeit just numerical (i.e. not statistically significant), impact on patient satisfaction. This seems plausible and could result from already having knowledge about the disease, as explicitly stated in some comments.

An FDC lasting more than 20 min was associated with a higher patient satisfaction. This is not surprising as ample time is prerequisite to integrate the above mentioned factors leading to patient satisfaction into the FDC, e.g. to cover all the topics that are important to PwMS. Moreover, adequate time is needed to inform patients emphatically about their diagnosis, to address questions from patients and relatives, and finally to engage in shared decision making with regard to future DMT.

Regarding the non-alterable factors in our regression model, a diagnosis being made after 2011 resulted in a higher patient satisfaction. As we could demonstrate in previous publications [21, 22], this could be due to an accelerated diagnostic process as well as the approval of five new and highly effective drugs to treat MS between 2011 and 2018 [7, 27–29].

In addition, patients above the age of 40 tended to be more satisfied than patients with an age between 20 and 40 years at the FDC. To speculate, this could result from a more advanced life experience and that patients between 20 and 40 years receive the diagnosis in a very crucial span of life that includes important private and professional goals such as family and career planning.

The sex difference with regard to FDC satisfaction remains elusive, however. In our study, men were more frequently satisfied with the FDC than woman. Further research should be dedicated to sex and gender differences in diverse aspects of the management of MS patients.

This study has some limitations. First, self-reported data can be affected by biases, such as recall bias, over- and underreporting. Moreover, we did not include information on comorbidities and cognitive functions at the time of the diagnosis that might have influenced the perception of the FDC as well. Furthermore, an ad hoc questionnaire to address the analyzed topic was added to the regular 6-month follow-up questionnaire because no validated instruments or surveys existed. However, questionnaire development included different quality control steps, in particular internal peer review and pilot testing by persons with MS. By contrast, our study's strengths include the comparatively large sample size and the detailed survey and database. Whether a positive experience of the FDC also leads to improved patient satisfaction, long-term motivation and adherence to therapeutic intervention seem plausible, but still await conclusive demonstration.

Conclusion

A high patient satisfaction with the FDC results from a clear communication of the diagnosis, a conversation of at least 20 min covering many MS relevant topics, the presence of a close relative or a significant other and shared decision making with regard to future DMT.

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Author contributions All authors contributed to the study conception and design as well as data collection. Statistical analysis were performed by LB, VvW and CPK. The first draft of the manuscript was written by CPK, LB and VvW and all authors commented on previous versions of the manuscript. All authors read and approved the final manuscript.

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Compliance with ethical standards

Conflicts of interest CPK has received honoraria for lectures as well as research support from Biogen, Novartis, Almirall, Bayer Schweiz AG, Teva, Merck, Sanofi Genzyme, Roche, Celgene and the Swiss MS Society (SMSG). CG: The Employer Department of Neurology, Regional Hospital Lugano (EOC), Lugano, Switzerland receives financial support from Teva, Merck Serono, Biogen Idec, Bayer Schering, Genzyme, Roche and Novartis. The submitted work is not related to these agreements. CP has received travel support and participated to advisory board for Biogen Idec, Genzyme, Novartis and Roche. PC has received honoraria for speaking at scientific meetings, serving at scientific advisory boards and consulting activities from: Abbvie, Actelion, Almirall, Bayer-Schering, Biogen Idec, EISAI, Genzyme, Lundbeck, Merck Serono, Novartis, Pfizer, Teva, and Sanofi-Aventis; his research is also supported by the Swiss Multiple Sclerosis Society, the Swiss National Research Foundation and the SOFIA Foundation. AS received speaker honoraria and/or travel compensation for activities with Almirall Hermal GmbH, Biogen, Merck, Novartis, Roche, and Sanofi Genzyme; none related to this work. LA served on scientific advisory boards for Novartis Pharmaceuticals, Merck, Biogen, Sanofi Genzyme, Roche and Bayer; received funding for travel and/or speaker honoraria from Biogen, Sanofi Genzyme, Novartis, Merck Serono, Roche, Teva and the Swiss MS Society. LB, MP, JK, and VvW have nothing to disclose.

Ethical standards The SMSR was approved by the Cantonal Ethics Committee Zurich (Study number PB-2016-00894) and has been per-

formed in accordance with the ethical standards laid down in the 1964 Declaration of Helsinki and its later amendments, and every patient has signed an informed consent prior to study entry.

References

1. Ware JE Jr, Davies AR (1983) Behavioral consequences of consumer dissatisfaction with medical care. Eval Progr Plan 6:291–297
2. Becker MH, Malman LA (1980) Strategies for enhancing patient compliance. J Community Health 6:113–135
3. Marquis MS, Davies AR, Ware JE Jr (1983) Patient satisfaction and change in medical care provider: a longitudinal study. Med Care 21:821–829
4. Miller RH, Williams PC, Napolitana G, Schmied J (1990) Malpractice: a case–control study of claimants. J Gen Intern Med 5:244–248
5. Barry MJ, Edgman-Levitan S (2012) Shared decision making—pinnacle of patient-centered care. N Engl J Med 366:780–781
6. Charles C, Gafni A, Whelan T (1997) Shared decision-making in the medical encounter: what does it mean? (or it takes at least two to tango). Soc Sci Med 44:681–692
7. Kamm CP, Uitdehaag BM, Polman CH (2014) Multiple sclerosis: current knowledge and future outlook. Eur Neurol 72:132–141
8. Solari A, Acquarone N, Pucci E et al (2007) Communicating the diagnosis of multiple sclerosis—a qualitative study. Mult Scler 13:763–769
9. Janssens AC, van Doorn PA, de Boer JB, van der Meché FG, Passchier J, Hintzen R (2003) Impact of recently diagnosed multiple sclerosis on quality of life, anxiety, depression and distress of patients and partners. Acta Neurol Scand 108:389–395
10. Solari A (2014) Effective communication at the point of multiple sclerosis diagnosis. Mult Scler 20:397–402
11. Giordano A, Lugaresi A, Confalonieri P et al (2014) Implementation of the 'Sapere Migliora' information aid for newly diagnosed people with multiple sclerosis in routine clinical practice: a late-phase controlled trial. Mult Scler 20:1234–1243
12. Stacey D, Légaré F, Lewis K et al (2017) Decision aids for people facing health treatment or screening decisions. Cochrane Database Syst Rev 4:CD001431. https://doi.org/10.1002/14651858.CD001431.pub5.Review
13. Papathanasopoulos PG, Nikolakopoulou A, Scolding NJ (2005) Disclosing the diagnosis of multiple sclerosis. J Neurol 252:1307–1309
14. O'Connor P, Detsky AS, Tansey C, Kucharczyk W (1994) Effect of diagnostic testing for multiple sclerosis on patient health perceptions. Rochester-Toronto MRI Study Group. Arch Neurol 51:46–51
15. Solari A, Martinelli V, Trojano M et al (2010) An information aid for newly diagnosed multiple sclerosis patients improves disease knowledge and satisfaction with care. Mult Scler 16:1393–1405
16. Elwyn G, Laitner S, Coulter A, Walker E, Watson P, Thomson R (2010) Implementing shared decision making in the NHS. BMJ 341:c5146
17. Puhan MA, Steinemann N, Kamm CP et al (2018) A digitally facilitated citizen-science driven approach accelerates participant recruitment and increases study population diversity. Swiss Med Wkly 148:w14623
18. Steinemann N, Kuhle J, Calabrese P et al (2018) The Swiss Multiple Sclerosis Registry (SMSR): study protocol of a participatory, nationwide registry to promote epidemiological and patient-centered MS research. BMC Neurol 18:111
19. Barin L, Salmen A, Disanto G et al (2018) The disease burden of Multiple Sclerosis from the individual and population perspective: which symptoms matter most? Mult Scler Relat Disord 25:112–121
20. R Core Team L (2017) R: a language and environment for statistical computing. R Foundation for Statistical Computing, Vienna. https://www.r-project.org/
21. Barin L, Kamm CP, Salmen A et al (2019) How do patients enter the healthcare system after the first onset of multiple sclerosis symptoms? The influence of setting and physician specialty on speed of diagnosis. Mult Scler. https://doi.org/10.1177/1352458518823955**(published online)**
22. Kaufmann M, Kuhle J, Puhan MA et al (2018) Factors associated with time from first-symptoms to diagnosis and treatment initiation of Multiple Sclerosis in Switzerland. Mult Scler J Exp Transl Clin 4:2055217318814562. https://doi.org/10.1177/2055217318814562. eCollection 2018 Oct-Dec
23. Ben-Zacharia A, Adamson M, Boyd A et al (2018) Impact of shared decision making on disease-modifying drug adherence in multiple sclerosis. Int J MS Care 20:287–297
24. Brown H, Gabriele S, White J (2018) Physician and patient treatment decision-making in relapsing-remitting multiple sclerosis in Europe and the USA. Neurodegener Dis Manag 8:371–376
25. Kessels RP (2003) Patients' memory for medical information. J R Soc Med 96:219–222
26. Sherlock A, Brownie S (2014) Patients' recollection and understanding of informed consent: a literature review. ANZ J Surg 84:207–210
27. Hauser SL, Bar-Or A, Comi G et al (2017) Ocrelizumab versus interferon beta-1a in relapsing multiple sclerosis. N Engl J Med 376:221–234
28. Montalban X, Hauser SL, Kappos L et al (2017) Ocrelizumab versus placebo in primary progressive multiple sclerosis. N Engl J Med 376:209–220
29. Gold R, Kappos L, Arnold DL et al (2012) Placebo-controlled phase 3 study of oral BG-12 for relapsing multiple sclerosis. N Engl J Med 367:1098–1107 **(Erratum in: N Engl J Med 367: 2362)**