

FEMALE SEXUAL FUNCTION

Sexual Dysfunction in Women With Multiple Sclerosis: Expectations Regarding Treatment and Information, and Utility of the SEA-MS-F Questionnaire



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ABSTRACT

Introduction: Sexual dysfunction is a common complaint in female with multiple sclerosis (MS), however this problem is not often considered in the medical and psychological care.

Aim: To evaluate expectations regarding treatment and information for sexual dysfunction in women with multiple sclerosis using the SEA-MS-F (Sexual Dysfunction Management and Expectations Assessment in Multiple sclerosis - Female) questionnaire, and to gain an understanding of the relationship between their expectations, demographic factors and medical factors known to promote sexual dysfunction.

Methods: A prospective epidemiological, descriptive, analytical, multicentre study was carried out over 15 months on adult women suffering from MS. The SEA-MS-F was used to evaluate expectations regarding their sexuality and sexual activity.

Main Outcome: Measure 87 women were included. Mean age was 47 years and the mean time since MS diagnosis was 14 years.

Results: 59.8% reported sexual dysfunction, but only 22.4% of the participants had raised the subject with a professional. With regards to expectations, 68% of the women wanted information about sexual dysfunction and 80% of women with sexual difficulties wanted treatment. High expectations correlated with the presence of sexual dysfunction, a regular sexual partner and with milder ambulatory handicap. There were no correlations between expectations and age, time since MS diagnosis, fatigue or being postmenopausal. The SEA-MS-F questionnaire was perceived as useful by 63.4% of the women and 90% felt that it could help doctors to treat sexual dysfunction.

Conclusion: To date, the SEA-MS-F is the only questionnaire validated in women with MS for the evaluation of sexual expectations and in the present study the women felt strongly that it represented a useful way for them to introduce and then discuss the subject of their sexual dysfunction with their doctor. **Audrey S-B, Marion R, Béatrice M, et al. Sexual Dysfunction in Women With Multiple Sclerosis: Expectations Regarding Treatment and Information, and Utility of the SEA-MS-F Questionnaire. Sex Med 2022;10:100502.**

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Key Words: Women; Multiple Sclerosis; Sexual Dysfunction; Expectations; Questionnaire SEA-MS-F

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INTRODUCTION

Multiple sclerosis (MS) is the primary cause of progressive neurological disability in young adults¹ and particularly affects women. Among the many neurological disorders secondary to MS, 40–95% of women have experienced sexual dysfunction (SD) which is more common than in other populations.^{2–10} Some studies have shown that SD could have greater impact on moral and quality of life than some of the physical impairments caused by MS.¹¹ Yet, while 83% of women with MS have indicated that they would like to talk about it, 63–94% have never mentioned this problem to their doctor.^{12,13}

This notable contrast between needs and what is done can be multifactorial: social taboo concerning sexuality both for patients and their clinicians, lack of questions regarding patients' sex lives, SD which is "pushed into background" by other problems caused by MS.

Commonest barriers to help-seeking for SD in MS reported by patients were dominance of neurological symptoms, presence of family and/ or of friends and not being asked; while health care professionals reported presence of family or friends, lack of knowledge about SD, and inadequate time during consultation.¹⁴

Sexual health has been defined by the World Health Organisation as, "a state of physical, emotional, mental and social well-being in relation to sexuality," and being an integral part of health and quality of life and can therefore not be resumed to the presence or not of symptoms.¹⁵ Sexual function in all people with neurological disorders must be considered holistically.¹⁶ To improve the treatment of SD in women with neurological disorders, therefore, it is essential to not just treat their symptoms but also to evaluate their expectations in terms of both their sexuality and their individual SD. We therefore decided to investigate this topic using a questionnaire-based approach that was centred on the expectations of individual women with MS in terms of their sexual function, rather than using a more classical approach that only analysed SD symptoms.

Different self-report questionnaires have been specifically validated for the evaluation of sexual function in women^{17,18}: the Female Sexual Function Index (FSFI),¹⁹ and 3 specifically in MS: the Multiple Sclerosis Intimacy and Sexuality Questionnaire in long (19 items) et short form (15 items) (MSISQ 19 and 15)^{11,20} and the Sexual dysfunction management Assessment and Expectations in Multiple Sclerosis - Female (SEA-MS-F).²¹ The first 3 from this list evaluate only symptoms, and the SEA-MS-F is the only one who evaluates patient expectations. Briefly, the SEA-MS-F was intended to assess the expectations defined as desires, hopes, wishes or entitlements related to clinical events.^{21,22}

The primary aim of this study was, therefore, to use the SEA-MS-F to evaluate the expectations of women with MS with regards to information and treatment for SD. Secondary aims were to (i) evaluate the relationship between patient expectations and known predisposing demographic and medical factors to SD; (ii) evaluate the women's perception of the utility of the SEA-MS-F

questionnaire and (iii) identify the best context expected by women for the discussions about sexuality with their healthcare team.

MATERIAL AND METHODS

Study Design

This study was epidemiological, descriptive, and analytical, prospective, and multicentre.

Participants

All women attending consultations in the physical and rehabilitation medicine departments of the Foundation Ildys (Roscoff), CHRU de Brest, Pole Saint-Hélier (Rennes), Centre Mutualist de Kerpape (Lorient), and the neurological department of the CHRU de Brest between February 2017 and July 2018 were eligible for inclusion. Inclusion criteria were female patients with MS, at least 18 years of age, able to understand and complete a self-report questionnaire and provided informed consent.

The exclusion criteria were patients under guardianship, patients seen in urgent consultations and pregnant patients.

Ethical Considerations

Eligible patients received an information note that involved detailed explanation. During medical consultation, doctor explained the study and gave them the opportunity to ask questions. The participant was informed about the option not to participate or to withdraw of the study at any time. For patients who accepted to participate, the investigator signed a non-opposition form. Approval was granted by the National Commission for Data Protection and Liberties: all the questionnaires were anonymized. According to current French regulations, ethical approval is not required for this type of study.

Procedure

At the end of the medical consultation, participants were shown into a room where they could be quiet and asked to complete a self-report questionnaire with 4 sections (supplementary data). The topics included in each section were:

Part 1: clinical and demographic factors (age, time since diagnosis, postmenopausal (yes/no), ambulatory capacity, presence of urinary/faecal incontinence or constipation, fatigue and mood).

Part 2: sexuality (sexual activity, regular sexual partner, presence of SD, and relationship to their MS).

Part 3: the SEA-MS-F questionnaire (8 questions);

The SEA-MS-F was published by a French team in 2014 and has been validated in both French and in English (see supplementary data). It is, to our knowledge, the only currently available, validated questionnaire that evaluates the sexual expectations of women with MS. The questionnaire has 8 questions and the responses to each are scored from 0 to 4 (0 = no

expectation to 4 = very high expectation). The total available score is 32. The SEA-MS-F evaluates expectations in 3 domains:

1. General expectations regarding the patient's sexuality
Specific expectations regarding the patient's SD symptoms
2. Reasons for seeking SD treatment

Part 4: the perceived utility of the SEA-MS-F questionnaire.

The questionnaire took, on average, 20 minutes to complete. Anonymous completed questionnaire was placed in an anonymized envelope and sealed. Then anonymous data was collected in an excel spreadsheet by independent data manager.

Statistical Analysis

Primary Objective. Descriptive analyses were carried out: means, standard deviations, medians, interquartile intervals, minima and maxima were calculated for the quantitative data (age, time since diagnosis and total SEA-MS-F score); numbers and frequencies were calculated for qualitative variables (SD, fatigue, mood, postmenopausal, urinary self-catherization, urinary incontinence, faecal incontinence, constipation, regular sexual partner, sexual activity, ambulatory capacity and SDs that the women considered to be related to their MS. The scores of the 8 SEA-MS-F questions (Appendix 1) were described as numerical variables (score from 0 to 4).

Secondary Objectives. Bivariate analyses were carried out to evaluate the relationship between the qualitative and numerical variables (questions 1 and 2 of the SEA-MS-F). In order to do this, the scores of the SEA-MS-F were first classed into groups:

scores of 0 or 1 were considered as having “low expectations” those with scores from 2 to 4 were classified as having “high expectations” (“moderately” to “extremely interested”) and, from within this group with high expectations, those whose scores were either 3 or 4 were further identified as having “very high expectations” (“very” to “extremely interested”).

The responses to the items of the SEA-MS-F were analysed by calculating the numbers of participants in each group, the proportion, and the 95% confidence interval.

The association between the qualitative SEA-MS-F variables and the numerical variables was analysed by comparing the median and interquartile scores for each response using a Wilcoxon or Kruskal-Wallis test. The association between the continuous data and qualitative 2-level variables (ie, “yes” or “no” answers) were evaluated using a student t test or (if the distribution was not normal) a Wilcoxon test.

For questions that had 3 answers (3-level variables) such as those regarding urinary incontinence (“no,” “yes <1/wk” and “yes >1/wk”) or ambulatory capacity (“non-ambulant,” “ambulant with gait aid” or “ambulant without a gait aid”) an ANOVA or Kruskal-Wallis test was used, depending on the distribution.

A Spearman correlation coefficient (and 95% confidence interval) was calculated to evaluate the relationship between numerical and quantitative variables. No correction for multiple testing was applied in order not to affect the power. $P < .05$ was used for all analyses. Data input was carried out by the Foundation Ildys clinical research unit.

A sample size calculation was not carried out because, to our knowledge, no data regarding responses to the SEA-MS-F are available, other than the primary publication, on which to base such a calculation.

Table 1. Participant characteristics (n = 87)

Participant characteristics	Quantitative variables	Mean \pm SD
	Age	47.3 \pm 10.1 (y)
	Time since MS diagnosis	14 \pm 8.9 (y)
	Total SEA-MS-F score	19.1 \pm 8.6
	Qualitative variables	Numbers (%)
	Postmenopausal*	41 (48.8%)
Ambulatory capacity	Walks with no assistive devices	57 (67.1%)
	Walks with assistive devices	16 (18.8%)
	Non-ambulant	12 (14.1%)
Urinary incontinence	No	25 (29.8%)
	<1/wk	35 (41.7%)
	>1/wk	24 (28.6%)
	Self-catherization*	22 (28.2%)
	Faecal incontinence*	18 (21.2%)
	Constipation*	37 (43.5%)
	Fatigue (moderate to high)	70 (81.4%)
	Thymus (positive)	65 (75.6%)
Sexual information	Sexually active*	59 (69.4%)
	Regular sexual partner*	63 (75.9%)
	Sexual dysfunction*	49 (59.8%)
	MS-related sexual dysfunction*	47

*Numbers (%) correspond to “yes” responses.

Table 2. Responses to the SEA-MS-F questionnaire

		Numbers (%)	Evaluation of expectations:SEA-MS-F questionnaire	
			Moderately to extremely interested (Score 2 à 4)Numbers (%) - CI 95%	Very to extremely interested (Score 3 à 4)Numbers (%) - CI 95%
Question 1 Information	0	9 (11%)	56 (68.3% - [57%; 77.9%])	39 (47.6% - [36.5%; 58.8%])
	1	17 (20.7%)		
	2	17 (20.7%)		
	3	23 (28%)		
	4	16 (19.5%)		
Question 2 Treatment	0	5 (8.3%)	48 (80% - [67.3% - 88.8%])	30 (50% - [37.7%; 62.3%])
	1	7 (11.7%)		
	2	18 (30%)		
	3	21 (35%)		
	4	9 (15%)		
Question 3 Desire	0	6 (10.2%)	43 (72.9% - [59.5%; 83.3%])	30 (50.8% - [37.6%; 63.9%])
	1	10 (16.9%)		
	2	13 (22%)		
	3	22 (37.3%)		
	4	8 (13.6%)		
Question 4 Arousal	0	9 (15.3%)	45 (76.3% - [63.1%; 86%])	27 (45.8% - [32.9%; 59.2%])
	1	5 (8.5%)		
	2	18 (30.5%)		
	3	19 (32.2%)		
	4	8 (13.6%)		
Question 5 Orgasm	0	7 (12.1%)	43 (74.1% - [60.7%; 84.4%])	30 (51.7% - [38.3%; 64.9%])
	1	8 (13.8%)		
	2	13 (22.4%)		
	3	20 (34.5%)		
	4	10 (17.2%)		
Question 6 Improvement of self-image	0	6 (10.5%)	44 (77.2% - [63.8%; 86.8%])	29 (50.9% - [37.4%; 64.2%])
	1	7 (12.3%)		
	2	15 (26.3%)		
	3	19 (33.3%)		
	4	10 (17.5%)		
Question 7 For self	0	3 (5.2%)	47 (81% - [68.2%; 89.7%])	39 (67.2% - [53.5%; 78.6%])
	1	8 (13.8%)		
	2	8 (13.8%)		
	3	18 (31%)		
	4	21 (36.2%)		
Question 8 For partner	0	3 (5.2%)	49 (84.5% - [72.1%; 92.2%])	40 (69% - [55.3%; 80.1%])
	1	6 (10.3%)		
	2	9 (15.5%)		
	3	18 (31%)		
	4	22 (37.9%)		

All statistical analyses were performed by the biostatistics unit of the Medical Research Department of the Catholic Institute Hospital of Lille using R software (version 3.4.2)

RESULTS

Participants

Between February 2017 and July 2018, 92 eligible women were asked to participate in the study. 87 were included in the

study and completed the questionnaire, 5 refused. The reasons for refusing to take part in the study (n = 5) were (i) patient didn't feel concerned (n = 3); (ii) time consuming questionnaire (n = 1); (iii) too painful experiences (n = 1).

Population description is shown in [Table 1](#). The mean age was 47 years and mean time since MS diagnosis was 14 years.

49 women (59.8%) declared having sexual difficulties among them 47 (95.9%) thought their difficulties were related to MS.

Main Aims

General Expectations. Most patients were interested in receiving more information about SD and its treatment: 68% (CI 95% [57%; 78%]) of participants had high expectations and 48% (CI 95% [37%; 59%]) very high expectations regarding the need of information about SD. 80% (CI 95% [67%; 89%]) had high expectations and 50% (CI 95% [38%; 62%]) very high expectations regarding the possibility of treatment for their own SD (Table 2).

Secondary Aims

Specific Expectations and Reasons for Wanting Treatment. Concerning patients with SD, most of them had high expectations regarding possibility of treatment for reduction in sexual desire (72.9%), difficulties in sexual arousal (76.3%) or in achieving orgasm (74.1%). 77.2% of women expected that SD treatment would help them to improve their own self-esteem. Motivations for asking treatment were for themselves (81%) and for their partner's benefit and/or for their relationship as a couple (85%) (Table 2).

Relationship Between Demographic and Medical Factors and General Expectations. Factors significantly related to high or very high information's needs about SD were (i) the presence of SD ($P = .0035$) and (ii) prior discussion about SD with a health professional ($P = .0005$). Factors significantly related to high expectations about treatment for SD were (i) the presence of SD ($P = .036$), (ii) prior discussion about SD with a health professional ($P = .00014$), (iii) having regular sexual partner ($P = .014$) and ability of walking with or without aid ($P = .017$). The total SEA-MS-F score was significantly higher for women who declared that they (i) had experienced SD ($P = .0016$), (ii) had a regular sexual partner ($P = .04$) and (iii) had already discussed the subject with a health professional ($P = .0001$).

There was no correlation ($P > .05$) between general expectations (SEA-MS-F Q's 1 and 2) or total SEA-MS-F score and age, being postmenopausal, the time since MS diagnosis, self-reported fatigue levels or urinary/faecal incontinence (Table 3).

Utility of the SEA-MS-F. Concerning de SEA MS F questionnaire, 83% of participants considered the SEA-MS-F to be a useful tool (CI 95% [72%; 91%]). 70% [57%; 79%] agreed that the questionnaire should be proposed in usual care to help patients discussing sexuality with their doctors and 90% [79%; 95%] agreed that it could help doctors to better treat SD (Table 4).

Best Context to Discuss Sexuality. Only 19 participants (of 87) had already discussed about SD with a health professional (a doctor for 16).

Most participants wanted the subject of sexuality and SD to be initiated by health professionals (65.3%). 42.9% chose first their neurologist and then their physical medicine and rehabilitation doctor or their general practitioner (29.9% each). They preferred at 60.5% to mention the SD subject in a follow-up visit, rather than in specific consultation or urodynamic examination. Modality of subject approach was a discussion for 61.5%, a questionnaire followed by a discussion for 35.9% and completion of a questionnaire only for 10%.

DISCUSSION

This is the first study to our knowledge, except the SEA-MS-F publication, investigating women's expectations about sexuality and SD in MS, and not only symptoms.

This study revealed that most of participants expected information on SD even if they are not directly concerned so far. Indeed, while 59% of the participant reported suffering from SD, more than 68% expected to have information on MS-related sexual difficulties. However only 22% of MS patients reported that they had already discussed the subject with a health professional. This finding is similar to that of Moreira et al who found that only 17% of 750 women had discussed their SD with their doctor, while 33.7% declared lack of sexual interest, 25.2% lack of pleasure in sex and 23.6% inability to reach orgasm.²³ Furthermore, our results highlight those women with MS don't have information and/or treatment about SD as they expected.

The high level of women's expectations about SD should encourage MS specialised health care professional to improve their approach of SD in MS. 1 issue related to the diagnosis of SD is the private nature of sexuality, which can inhibit both patients and/or health professionals in engaging in discussion about sex.²⁴ Data from our study suggested that a questionnaire can provide a convenient method to overcome such personal barriers and so enable constructive discussions regarding needs, problems, and solutions. The SEA-MS-F has good psychometric properties, excellent internal coherence and excellent acceptability and so would be suitable for both clinical practice and research purposes.^{17,21} In our study 83% of participants were at least moderately interested in the idea of the SEA-MS-F questionnaire being used to help patients with MS; 90% of participants agreed with the suggestion that it could help doctors to better treat SD. Thus, we believe that SEA-MS-F questionnaire could be used to evaluate SD expectations, as the "non asked question" was described as a barrier by Tudor.¹⁴

Our results did not find a relationship between participants' medical data, demographic factors and expectations regarding SD information and/or treatment. This contrasted with existing studies of MS SD.^{6-10,14,25} We believe that the absence of an influence of such variables as age, fatigue, mood, menopause, time since diagnosis and urinary and/or faecal incontinence was due to the fact that we evaluated patient expectations and not

Table 3. Relationship between medical and demographic factors, and general expectations (questions 1 et 2) and total SEA-MS-F score

Qualitative factors	Question 1 SEA-MS-F			Question 2 SEA-MS-F			Total SEA-MS-F Score					
	No	Yes	<i>P</i>	No	Yes	<i>P</i>	No	Yes	<i>P</i>			
Sexual dysfunction	1,5 [1; 2,8]	3 [2; 3]	.0035 [†]	2 [0; 3]	3 [2; 3]	.036*	8 [5,4; 19]	22,5 [15,5; 26]	.0016 [†]			
Subject raised	2[1; 3]	3 [3; 4]	.0005 [‡]	2 [1; 3]	3 [3; 3,2]	.00014 [‡]	18 [8,5; 23]	24 [23; 27]	<.0001 [‡]			
Regular partner	2 [1; 3]	2 [1; 3]	.13	2 [0; 3]	3 [2; 3]	.014*	14 [4,8; 22]	21,7 [15,25]	.04*			
Postmenopausal	3 [1; 3]	2 [1; 3]	.46	3 [2; 3]	2[2; 3]	.4	23 [14,2; 25,6]	20,8 [14,2; 23,8]	.49			
Self-catherisation	2[1; 3]	3 [1,2; 3,8]	.43	2 [2; 3]	3 [2; 3]	.23	21,7 [11; 24]	23 [14,8; 26,8]	.53			
Faecal incontinence	2 [1; 3]	3 [1,2; 4]	.42	2,5 [2; 3]	3 [2; 4]	.33	20,6 [11,5; 24,5]	23,5 [20,8; 29]	.11			
Constipation	2,5 [1; 3]	2 [2; 3]	.71	3 [2; 3]	2 [2; 3]	.94	22 [13,24]	21 [14,5; 26]	.99			
Sexually active	2 [1; 3]	3[1; 3]	.23	2,5 [1,2; 3]	2,5 [2; 3]	.65	21 [8,8; 26,2]	21,7 [14,7; 24]	.53			
Fatigue	2 [1,8; 2,2]	3 [1;3]	.6	2 [2;2,8]	3 [2;3]	.43	17 [10,5; 21]	22 [14,7; 25]	.18			
Thymus	3 [1;3]	2 [1;3]	.54	2,5 [2;3]	2 [2;3]	.68	21,5 [19;24,8]	20,9 [11,5;24]	.67			
Urinary incontinence	No 2 [1;3]	<1/wk 2 [1;3]	>1/wk 3 [2;3]	.22	No 2 [1,8;3]	<1/wk 3 [2;3]	>1/wk 2 [2;3,5]	.68	No 18,5 [9;23]	<1/wk 21,1 [16,4;24,3]	>1/wk 23 [19;26]	.31
Ambulatory capacity	No aide 3 [3;1]	With aide 2 [1;3]	No 2 [1;3]	.51	No aide 3 [2;3]	With aide 3 [2,5;4]	No 2 [0,8;2]	.017*	No aide 23 [17;25,1]	With aide 22,5 [17,9;26,5]	No 13 [7,2;21,2]	.12
Quantitative factors	Rho		IC-95		Rho		IC-95		Rho		IC-95	
Age	-0,047		[-0.263; 0.178]		-0,134		[-0.404; 0.141]		-0,017		[-0.282; 0.253]	
Time since MS diagnosis	-0,102		[-0.32; 0.118]		-0,158		[-0.42; 0.124]		0,033		[-0.236; 0.293]	

Significance level:

* <5%.

† <1%.

‡ <0.1%.

Rho = Spearman's correlation; CI 95% = Confidence interval 95%; *P* = *P* value.

Table 4. Discussion context for sexual dysfunction

Discussion context		Numbers (%)
Subject raised		19 (22.4%)
<i>With whom?</i>	<i>Doctor</i>	16 (88.9%)
	<i>Physiotherapist</i>	2 (11.1%)
	<i>Nurse</i>	2 (11.1%)
	<i>Psychologist</i>	3 (16.7%)
	<i>Other</i>	1 (7.1%)
Participant's own initiative		25 (35.7%)
Professional's initiative		47 (65.3%)
<i>Which professional?</i>	<i>Neurologist</i>	33 (42.9%)
	<i>General practitioner</i>	23 (29.9%)
	<i>Rehabilitation doctor</i>	23 (29.9%)
	<i>Nurse</i>	17 (22.1%)
	<i>Professional not involved in MS care</i>	9 (11.7%)
	<i>Other</i>	11 (14.3%)
<i>How did the conversation arise?</i>	-	
	Discussion	48 (61.5%)
	Questionnaire	8 (10.3%)
	Questionnaire + Discussion	28 (35.9%)
	Medical follow-up consultation	46 (60.5%)
	Specific consultation	19 (24.7%)

the outwardly physical, and most easily measured, symptoms associated with SD.

Previous study reported a higher prevalence of SD in MS patients with increased physical disability.^{4–10,25} However, Calabro et al have noted a high SD prevalence (70%) in a sample of individuals younger than 55 years old, with lower ambulatory handicap suggesting that there is no direct relationship between locomotor disability and sexual problems.²⁶ In the present study, the participants with highest expectations regarding treatment for SD were ambulatory (either with or without aid). We believe that our results highlight the benefit of using the SEA-MS-F questionnaire to ask women directly about their sexual needs whatever ambulatory capacity or other MS symptoms (urinary, gastrointestinal, fatigue, mood etc).

Those women who were most positive regarding the use of a questionnaire or about the importance of discussing SD with a doctor were those who declared they had SD, a regular sexual partner and had already talked to a health professional. These women still wanted more information on MS-related sexual difficulties. This, we believe, reflected the fact that the patient's interviews and treatments had been inadequate or incomplete.

We believe that it is therefore important that doctors (both generalists and specialists) are made aware of these studies and

the importance of discussing sexual health issues, as well as receiving training in the most appropriate way to approach the subject in different situations. It seems important to support doctors in this work: training in communicating with patients who have MS on the subject of sex and sexuality is fundamental.^{27,28}

Communication regarding these issues should also be open and direct across the multidisciplinary team. This process needs to begin early in the care pathway and be a part of multidisciplinary discussions that includes specialists in both neurology, physical medicine and perineal disorders to ensure appropriate management and treatments in the light of each individual patient's disability.⁶

The questionnaire was judged as a positive tool to facilitate conversations about SD by 90% of the patients. Knowledge of such patient expectations is pertinent for the provision of a personalised, appropriate, and holistic approach to caring and supporting patients with MS.

Finally, the evaluation of expectations has been defined by the French Health Authority (HAS)²⁹ as a key component of the creation of an effective Therapeutic Patient Education plan (TPE), in better to affect their engagement and active participation in the management of their disease and its symptoms.

Limitations

1 limitation is the closed nature of the questions asked. The SEA-MS-F questionnaire provides an indirect method of questioning the patient in terms of their sexual expectations, however in order to fully understand the problem, it should be followed-up by a discussion with a doctor or another suitable healthcare professional. The questions in the other sections were based on existing medical and paramedical practice and organisation and participants did not have the opportunity to make suggestions regarding the context and methods of approach to the discussion of sexual function. However, most participants stated they preferred such discussions to occur during medical consultations, rather than with paramedical or psychology professionals which were also proposed.

The main limitation in this study was the small recruitment of the centres during the 15-month-study. Unfortunately, that may highlight the lack of interest in sexual topic of the medical community. However even if the number of participant may be considered as small, it provided interesting and relevant insight into patient expectations.

CONCLUSION

The expectations of patients with MS regarding their interest in their sexuality and in maintaining sexual function, as measured using the SEA-MS-F questionnaire, were high. This contrasted with the low rate of patients who reported having broached the subject with their doctor. The present study differed from other studies that evaluated SD because it focussed on the evaluation of patient expectations, regarding the factors that predispose to and are associated with SD.

The results support the need to obtain patient expectations in the early stages of the disease, regardless of the severity of their MS symptoms. Giving patients the opportunity to answer the SEA-MS-F questionnaire, seems to be a good way to overcome barrier between patients and healthcare professionals.

This makes it particularly important to manage patient expectations to improve the efficacy of any SD treatment or management. The discussion between the patient and the doctor with regard to sexuality and sexual function must therefore also include realistic goal setting as an aim of the treatment.

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SUPPLEMENTARY MATERIALS

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