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Opinions and clinical practices related to diagnosing and managing functional (psychogenic) movement disorders: Changes in the last decade

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Abstract

Background. There is large variability in the diagnostic approach and clinical management in functional movement disorders (FMD). This study aimed to examine whether opinions and clinical practices related to FMD have changed over the past decade.

Methods. A survey to members of the International Parkinson and Movement Disorder Society (MDS).

Results. We received 864/7689 responses (denominator includes non-neurologists) from 92 countries. Respondents were more often male (55%), younger than 45 (65%), and from academic practices (85%). Although the likelihood of ordering neurological investigations prior to delivering a diagnosis of FMD was nearly as high as in 2008 (47% versus 51%), the percentage of respondents communicating the diagnosis without requesting additional tests increased (27% versus 19%; $p=0.003$), with most envisioning their role as providing a diagnosis and coordinating management (57% versus 40%; $p<0.001$). Compared to patients with other disorders, 64% of respondents were more concerned about missing a diagnosis of another neurological disorder. Avoiding iatrogenic harm (58%) and educating patients about the diagnosis (53%) were again rated as the most effective therapeutic options. Frequent treatment barriers included lack of physician knowledge and training (32%), lack of treatment guidelines (39%), limited availability of referral services (48%), and cultural beliefs about psychological illnesses (50%). The preferred term for communication favored “functional” over “psychogenic” ($p<0.001$).

Conclusions. Attitudes and management of FMD have changed over the past decade. Important gaps remain in the education of neurologists about the inclusionary approach to FMD diagnosis, and improving access to treatment.

Introduction

Functional movement disorders (FMD) refer to involuntary abnormal movements that are inconsistent and incongruent with the phenotypic range of other movement disorders.(1) In recent years, the terminology has shifted from “psychogenic” to “functional” movement disorders,(2) emphasizing the conceptual evolution from brain-mind dualism to a biopsychosocial illness model including alterations in sensorimotor and limbic brain circuits.(3-7) FMD is estimated to represent from 5 to 25% of patients seen in specialized movement disorder centers.(8) Despite the high frequency of this disorder in neurological settings, these patients have historically been poorly diagnosed and managed. Although it is established that FMD is a ‘rule in’ diagnosis with “positive criteria” for phenotype-specific diagnosis,(9-11) an exclusionary approach to diagnosis is often used, with unnecessary or harmful diagnostic investigations and pharmacotherapy.(12) A decade-old survey of members of the International Movement Disorder Society (MDS) with experience in FMD treatment found substantial variability regarding opinions and clinical practices associated with FMD. We aimed to conduct an updated survey to determine if opinions and clinical practices have changed.

Methods

The 2008 survey was reviewed and modified by members of the MDS FMD Study Group. Questions were added to address new education and care practices. The resulting 21-item survey (Supplementary material) was sent to all 7,689 MDS members via the MDS secretariat. Only practicing neurologists with experience in evaluating patients with FMD were asked to participate, which reduces the denominator to under 5,000 potential respondents (member qualifications not reported by MDS). The survey remained open for six weeks between August 16 and September 28, 2018, with three reminder emails sent during this period. Participants were asked demographic information on age, gender, country of practice and average number of patients under their care. Informed consent was not required, since no personal identifying information was collected. Study data were collected and managed using REDCap electronic data capture tools. (13) The study protocol was approved by the University of Louisville Institutional Review Board.

Statistical Analysis

The survey data were exported from REDCap into STATA 15.1 for analyses (StataCorp LLC, College Station, TX 77845, USA). Clinical characteristics, demographic characteristics, and survey responses were summarized using descriptive statistics. Mean and standard deviation (SD) were used to summarize Likert scale data. All the categorical data including Likert scale data and categorized data from continuous variables were summarized using frequency and proportion. Frequencies and percentages from each response from the previous survey were compared with current survey data using Fisher's exact test or Chi square test and analyzed according to gender, age, country, training length, patient load, type of practice, location of practice, and years of practice using Chi square tests. Spearman rank correlation (r) was determined among ratings within each category of responses (diagnosis, treatment, prognosis, and ability to manage).

Results

There were 864 responses from MDS members in 92 countries, most from the US (21%), Europe and Canada (35% combined). Compared to the previous survey, a higher proportion of respondents practiced in countries outside North America and Europe (44% versus 25%; $p < 0.001$). One third of respondents evaluated more than 3 FMD patients per month compared to 21% in the prior survey (5% reported seeing over 11; previously 1%, $p < 0.001$) (Table 1).

A higher number of respondents reported identifying a co-morbid organic neurologic disorder "sometimes" or "frequently" (41% versus 20%, $p < 0.01$); 64% were "more" or "very concerned" about missing another organic diagnosis in FMD patients compared to non-FMD neurological patients. The personal preference in 29% of respondents was for disliking "somewhat" or "very much" seeing FMD patients (no comparison data available).

Reaching the Diagnosis

In order to reach a clinically definite FMD diagnosis, the majority of respondents rely exclusively on neurologic examination (78%; previously 71%; $p=0.007$), incongruence of movements with a classical movement disorder (61%; previously 72%; $p<0.001$), and inconsistency over time (52%; previously 57%; $p=0.1$) (Table 2). Although DSM-5 no longer requires it, 12% of respondents required evidence of an emotional disturbance for a clinically definite diagnosis of FMD compared to 18% previously ($p=0.005$). Suggestibility, a maneuver to change the movements, was less commonly used to diagnose FMD (“often” or “always” in 43%; previously 47%; $p<0.001$). Use of a placebo to alter or abolish the phenotype with an inert intervention, was “never” (48%; previously 51%) or “rarely” (25%; previously 24%; $p=0.7$) used for diagnostic purposes (Table 2). Placebo use was more commonly reported outside the US (“sometimes”, “often”, or “always” in 32% versus 6%, $p<0.001$).

Even when clinical features were incongruent and inconsistent with the diagnosis of FMD, 47% of respondents requested standard neurological investigations to rule out other neurologic diseases before diagnosing the patient with FMD, compared to 51% in 2008, a non-significant difference (Figure 1). On the other hand, the percentage of respondents informing patients about a clinically definite diagnosis of FMD during their initial assessment, without requesting additional investigations, increased from 19% to 27% ($p=0.003$). Respondents in the US employed this approach over twice as often as those outside the US (56% versus 19%; $p<0.001$). The likelihood of ordering neurological investigations prior to delivering a diagnosis of FMD was also dependent on the number of FMD patients seen per month: 38% of practitioners seeing ≥ 7 FMD patients per month did not routinely order additional diagnostic studies compared to 19% of those seeing ≤ 1 FMD patients per month ($p<0.001$). Neither age, gender, or number of years in practice affected the respondents’ approach.

Electrophysiology was used by 60% (versus 66% in 2008) on a regular basis for a laboratory-supported diagnosis of functional myoclonus or tremor; 33% (previously 24%) had no access to such laboratory studies. Only 7% (previously 9%) believed it was not useful in diagnosing FMD.

Electrophysiologic testing was more commonly used outside the US (for confirmation in “all” or “selected” cases in 45% versus 27%; $p < 0.001$); survey respondents outside the US were also more likely to discuss test results with patients to explain the diagnosis of FMD ($p < 0.001$).

The majority of respondents considered their main responsibility to provide a diagnosis and coordinate interdisciplinary management (57% versus 40% in 2008; $p < 0.001$). Only 1% restricted their role to providing the diagnosis (previously, 3%). Practitioners in small centers were less likely to coordinate long-term management compared to those from large city locations (36% versus 62%; $p = 0.005$).

Predictors of the Diagnosis

A non-FMD diagnosis was “somewhat” or “very/extremely” influenced by a prior “organic” diagnosis by an experienced neurologist (43%/30%); absence of associated non-physiologic deficits on neurologic examination (34%/33%), lack of psychiatric history (33%/22%), evidence of physical injury (37%/26%), and extremes of age (<6 or >75 years) (36%/31%). Male gender (69%), normal social function (45%), normal work load with little or no employment disruption (42%) were rated as “not influential” or “mostly not influential”.

Approach to Management

Respondents “always” or “most of the time” discussed positive signs on physical examination (49%), the potential for reversibility or improvement (90%), the potential role of psychological factors (85%), the diagnostic label (78%), and the changes in brain function (70%). Printed or online educational materials were “always” or “most of the time” provided by 82%. Survey respondents with most FMD patients per month were most likely to “always” or “most of the time” demonstrate positive physical signs on examination to patients compared with respondents with fewest FMD patient per month (59% versus 40%; $p = 0.003$).

In terms of treatment practices in 2008, two thirds of practitioners referred patients to psychiatrists or mental health specialists while also providing personal follow-up. Recognizing the importance of access to treatment providers on referral practices, we asked in the current survey to which services clinicians could readily refer patients for treatment in their region. Access was available to general psychiatry in 56%, neuropsychiatrist or a psychiatrist with FMD experience in 38%, general psychologist or psychotherapist in 40%, psychologist or psychotherapist experienced in FMD in 22%, rehabilitation or physiotherapy specialist in 49%, psychiatric inpatient services in 19%, inpatient multidisciplinary rehabilitation in 18% and other specialty clinics in 5%. Referrals to psychologists, rehabilitation specialists or physiotherapists was more readily available in the US compared to other countries ($p < 0.001$).

In cases with a dominant clinically definite diagnosis of FMD where a comorbid organic disorder was suspected, the majority of respondents (80%) chose to determine the major source of disability and prioritize treatment of that symptom, regardless of whether it was considered organic or functional (no previous data available for comparison).

Perceived Effectiveness of Treatment Strategies

Management modalities believed to be “very” or “extremely” effective by over one third of respondents were avoiding iatrogenic harm (58%), patient education (53%), referral to rehabilitation services (40%), and psychotherapy with antidepressive/anxiolytic treatment (35%). Most treatment strategies were rated higher in perceived effectiveness compared to 2008 (Figure 2A).

Limitations in Ability to Manage FMD Patients

Factors considered as “often” or “always” limiting the management of patients with FMD by over one third of respondents were cultural beliefs about psychological illnesses (50%; previously 40%),

missing availability of referral services (48%; previously 33%), lack of treatment guidelines (39%; not previously asked) and lack of physician knowledge and training (32%, not previously asked) (Supplementary Table S1). The role of ongoing litigation was less frequently cited as limiting FMD management (25%; previously 37%). Lack of physician knowledge and training and lack of treatment guidelines were more often cited as treatment barriers by respondents in non-US countries (37% versus 16% and 42 versus 25%, respectively; $p < 0.001$).

Predictors of Prognosis

Compared to 2008, greater weight in predicting a favorable prognosis was given to the type of movement (tremor or chorea vs. dystonia or ataxia), pharmacologic treatment of specific movement impairment, less extensive disability, and younger age when developing the movement disorder (Figure 2B). Similar to the prior survey, the most important factor in predicting a favorable prognosis was considered the acceptance of the diagnosis by the patient, rated as “extremely important” in 61% (previously 60%).

Terminology

Compared to 2008, the preferred terms for communication with other healthcare professionals shifted mostly to “functional” (63% in 2018 vs 46% in 2008) from “psychogenic” (35% in 2018 vs 59% in 2008) ($p < 0.001$, Figure 3A). “Functional movement disorder” was also the preferred term for communication with the lay public (87% in 2018 versus 37% in 2008) (Figure 3B).

Discussion

Expert opinions and clinical practices in managing FMD continue to vary widely among neurologists with movement disorder expertise. Despite efforts over the past decade to establish “positive” diagnostic criteria,^(9, 11) FMD remains an exclusionary diagnosis for nearly half of the MDS members with FMD treatment experience participating in this survey. A change in practice pattern

towards making an inclusionary clinical diagnosis of FMD, educating patients by demonstrating “positive signs”, and providing consistent educational resources were features among practitioners with the highest number of FMD patients per month, plausibly reflecting an increased comfort level with the certainty of the diagnosis. The significantly higher number of respondents evaluating more than three patients with FMD per month (34% vs. 21%) is likely reflective of better recognition of FMD rather than a true increase in prevalence. Differences in approaches to diagnosis and management of FMD were only partially explained by different practice patterns between countries, and were not due to differences in age, gender, or years in practice by survey respondents.

Challenges in Reaching a Diagnosis

Over one quarter of survey respondents were comfortable in communicating a diagnosis of FMD without requesting additional neurologic tests, a significantly higher percentage compared to a decade ago. Although 75% rely on positive signs on neurological examination to make a diagnosis of FMD, 64% were more concerned about misdiagnosis in FMD compared to other neurologic conditions, indicating a need for additional education in neurology training and continued medical education.(14, 15) Interestingly, incongruence of movements with a recognized movement disorder was less endorsed as a reliable way to reach a diagnosis of FMD (59% vs. 71%). This may reflect an increasing awareness that diagnosis by incongruity with other neurological conditions is, in many ways, also a diagnosis of exclusion and perhaps increasing recognition of unusual and hard to classify movement disorder phenotypes with genetic or autoimmune background.(16, 17)

Adding to diagnostic uncertainty, the percentage of respondents identifying co-morbid “functional” and “organic” neurologic disorders “sometimes” or “frequently” doubled compared to the last survey (41% versus 20%). Although comorbid FMD and neurodegenerative disorders have recently been described and may be underappreciated in the literature,(18, 19) our survey cannot determine the true prevalence of neurologic comorbidities in FMD, highlighting an important knowledge gap.

As the co-occurrence of FMD with an “organic” disease diagnosis is not rare, additional baseline diagnostic investigation may be justified even in people with clinically definite FMD.

The new survey appropriately reflected the recognition that psychological stress factors are not a required feature for a clinically definite diagnosis of FMD. Nevertheless, 12% of survey respondents were unaware of the fact that an emotional disturbance is no longer a required diagnostic feature for functional neurologic disorder per DSM-5(20). We found a high percentage of practitioners performing electrophysiologic testing on a regular basis for diagnostic confirmation of functional tremor and myoclonus, with considerable differences between countries in practice patterns and access to testing. Survey respondents outside of the US were significantly more likely to use electrophysiology to support an FMD diagnosis, and were about twice as likely to have access to such testing. The lack of movement disorder specialists trained in electrophysiologic testing in the US and elsewhere remains a barrier towards “laboratory-supported” diagnostic criteria for functional tremor and myoclonus.(10, 11) For other phenotypes, the absence of a laboratory “gold standard” to distinguish FMD from “organic” disorders remains a challenge.(21) The use of placebo for diagnostic purposes was more commonly reported in countries outside the US which may reflect differences in cultural and litigation practices.

It is important to note that several studies have shown the rate of misdiagnosis in FMD to be low and not unlike that of other neurologic disorders.(22, 23) In fact, there is reason to believe that functional neurologic disorders are often undiagnosed and may be “hiding in plain sight.”(24) By contrast, almost two thirds of our survey respondents indicated to be “very concerned” or “more concerned” about missing a separate organic diagnosis in patients with FMD compared to patients with other diagnoses.

Challenges in Management and Prognosis

As is the case with diagnosis, the approach to management and prognostic factors continued to show considerable variability. The avoidance of iatrogenic harm and education of patients about their diagnosis were again rated as most important. Studies have not shown consistent benefit in outcomes from patient education alone compared to standard medical care, although patient education is arguably a desirable endpoint of its own.(25) Although over 50% of survey respondents acknowledged their role in providing ongoing care for patients with FMD beyond establishing the diagnosis, practitioners at small centers were only half as likely to assume this role, possibly due to general access problems in their practice or being less comfortable in managing FMD. It is also of concern that almost one third of respondents prefer not seeing patients with FMD in their practice, likely reflecting ongoing stigma towards this diagnosis, misinformation (e.g., confusion with malingering), and system-based issues such as lack of available treatment services.

Lack of access to both mental healthcare providers and rehabilitation specialists remain important limitations for treatment. Compared to 2008, survey respondents indicated greater confidence for positive treatment outcomes but the lack of available treatment services perceived as a greater barrier (48% versus 33%). This may reflect an increased awareness of the efficacy of these treatments and therefore a greater urgency to make a referral than before. Of note, our survey only asked for “ready access to treatment providers” and is therefore not directly reflective of actual treatment practices. “Cultural beliefs about psychological illnesses” was highlighted as a treatment barrier by half of survey respondents, indicating an opportunity for improved education and advocacy. Finally, lack of treatment guidelines and lack of physician knowledge and training were seen as important barriers especially in countries outside the US. The acceptance by patients of the diagnosis was again seen as the most important predictive factor of a favorable prognosis highlights the importance of engaging patients in their diagnosis and treatment. Towards this aim, a number of publications in recent years have outlined successful communication strategies in explaining a diagnosis of FND as well as techniques to improve patient engagement in therapy such as motivational interviewing.(26, 27)

Finally, we documented a clear change in the preference in terminology from “psychogenic” and “stress-related” towards “functional movement disorders” when communicating with both healthcare providers and the lay public. This change in terminology is reflected in the recent FMD literature,(2, 15) although we acknowledge a potential bias in the survey due to changing the wording in the stems of questions from “psychogenic” in 2008 to “functional”.

Limitations

This survey-based research may have biases introduced by a greater participation of clinicians from academic centers with interest in FMD. We could not calculate the percentage of movement disorders neurologists, primarily responsible for the care of these patients, because the MDS membership database lacks this information. We assume that the participation of non-clinicians is likely negligible. The current survey gained more responses from countries outside of the US compared to the past survey in 2008, which is a limiting factor in direct comparisons of treatment practices.

Conclusions

Opinions and practices in clinical management of FMD are changing. The majority of clinicians now acknowledge their role in coordinating care for patients and express greater optimism in benefits from treatment compared to a decade ago. Remaining gaps towards best practices exist in educating neurologists on reaching a diagnosis of FMD based on positive diagnostic signs rather than on an exclusionary approach. Importantly, limited access to treatment resources for FMD continues to represent a major obstacle in caring for patients with FMD and attenuating their disability.

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Legends

Figures

Figure 1. Approach to delivering the diagnosis in clinically definite FMD in 2008 versus 2018.

Columns marked with an asterisk indicate a p-value <0.05.

Figure 2A. Perceived effectiveness of specific treatment strategies; Figure 2B. Importance of various factors in predicting a better prognosis of FMD, survey results from 2008 versus 2018. Rows marked with an asterisk indicate a p-value <0.05.

Figure 3A. Preferred terms when communicating with medical professionals, when respondents were asked to rate 'top three'.

Figure 3B. Preferred terms when communicating with lay public, when respondents were asked to rate 'top three'.

Tables

Table 1. Demographics of Survey Respondents and Practice Characteristics

An asterisk (*) denotes an overall significant difference ($p < 0.05$) between survey responses in 2008 and 2018.

Table 2. Approaches in Reaching the Diagnosis of FMD

An asterisk (*) denotes an overall significant difference ($p < 0.05$) between survey responses in 2008 and 2018.

Supplementary Table S1. Limitations of Ability to Manage FMD

An asterisk (*) denotes an overall significant difference ($p < 0.05$) between survey responses in 2008 and 2018.

Ethical Compliance Statement

The study protocol was approved by the institutional review board at the University of Louisville. Given the survey-based nature of the study with no patient identifying information, no informed consent was required. We confirm that we have read the Journal's position on issues involved in ethical publication and affirm that this work is consistent with those guidelines.

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FM: has received speaking honoraria from Medtronic, Boston Scientific, Chiesi, Abbvie, Bial, Merz, Zambon; has served on the Advisory board for Merz UK; received royalties from Springer for the book "Disorders of movement"; serves on the Editorial Boards for Movement Disorders (Associate Editor) and Movement Disorders Clinical Practice.

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Authors' Roles

Kathrin LaFaver: conception, organization and execution of the study, writing the first draft of the manuscript

Alberto Espay: conception and organization of the study, review and critique of the manuscript

Jon Stone: conception and organization of the study, review and critique of the manuscript

Francesca Morgante: conception and organization of the study, review and critique of the manuscript

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Mark Hallett: conception and organization of the study, review and critique of the manuscript

Alok Dwivedi design and execution of the statistical analysis, review and critique of the manuscript

Anthony Lang: conception, organization and execution of the study, review and critique of the manuscript

Accepted Article

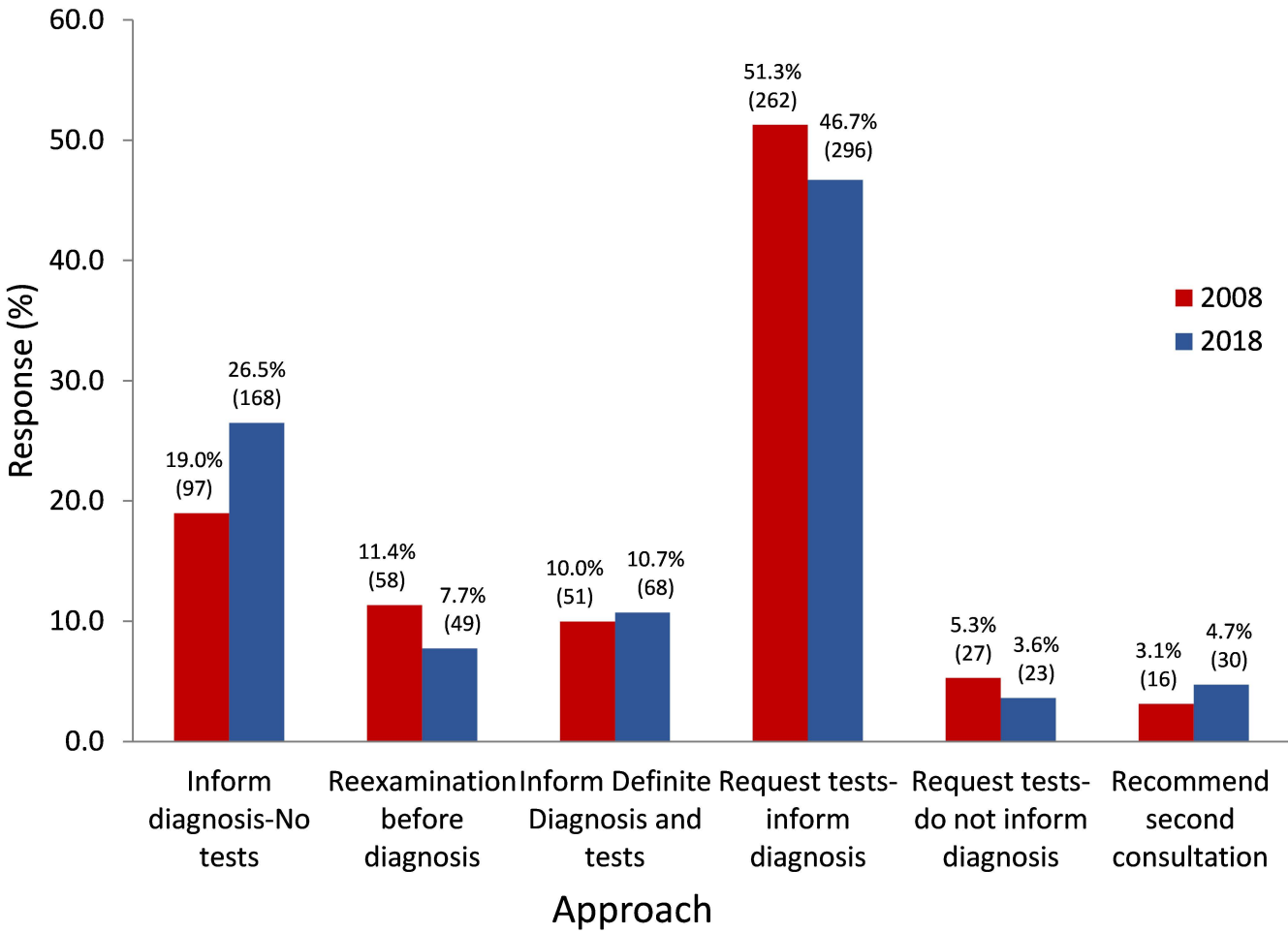
Table 1

Characteristics of Survey Respondents	2008		2018		p-value
	N	%	N	%	
Gender					<0.001*
Male	313	68	346	54.7	
Female	150	32	286	45.3	
Age (years)					<0.001*
25-35	72	16	189	29.8	<0.001
36-45	172	37	220	34.7	0.408
46-55	144	31	115	18.1	<0.001
56-65	59	13	85	13.4	0.786
>66	16	4	25	3.9	0.749
Country					<0.001*
US	199	43	135	21.3	<0.001
Europe + Canada	149	32	222	35.0	0.302
Others	118	25	277	43.7	<0.001
Years in practice (Post-Residency)					<0.001*
< 5 years	110	24	241	38.0	<0.001
6-10 years	88	19	116	18.3	0.814
11-15 years	85	18	81	12.8	0.013
16-20 years	67	14	64	10.1	0.030
>21 years	114	25	132	20.8	0.144
Length of fellowship training					0.036*
None	92	20	107	16.9	0.204
1 year	100	22	124	19.6	0.404
2 years	126	28	154	24.3	0.261
3 years	52	11	76	12.0	0.775
4 years	89	19	173	27.3	0.003
Type of practice					0.726
Academic clinician	133	29	191	30.1	
Academic clinician/researcher	255	55	348	54.9	

Community practice	77	17	95	15.0	
Practice setting					0.132
Small center	14	3	33	5.2	
City population > 50,000	161	35	236	37.2	
City population >1 million	285	62	365	57.6	
Number of FMD patients seen per month					<0.001*
< 1	148	32.0	141	22.3	<0.001
1-3	220	47.5	277	43.8	0.220
4-6	63	13.6	127	20.1	0.006
7-10	26	5.6	54	8.5	0.078
>11	6	1.3	34	5.4	<0.001
Number of movement disorder patients seen per month					<0.001*
< 30	63	13.7	167	26.3	<0.001
31-45	100	21.7	139	21.9	1.00
46-60	82	17.8	100	15.8	0.367
61-80	82	17.8	57	9.0	<0.001
>80	133	28.9	171	27.0	0.495
Presence of co-morbid organic neurologic disorder					<0.001*
Never	56	12.2	43	6.8	0.003
Very rarely	198	43.0	151	23.8	<0.001
Rarely	115	25.0	182	28.7	0.169
Sometimes	70	15.2	225	35.5	<0.001
Frequently	22	4.8	33	5.2	0.781

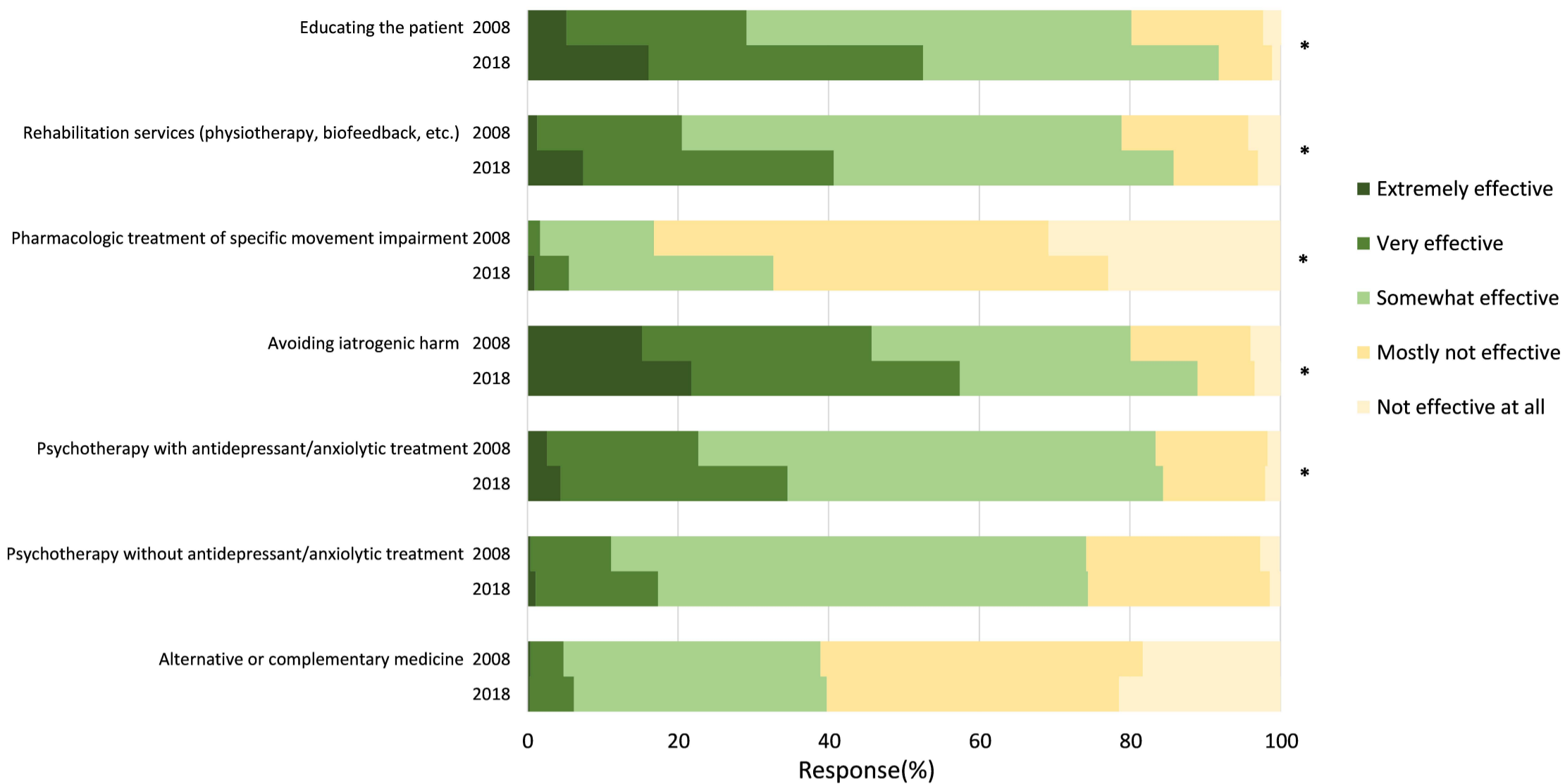
Table 2

	2008	2018	p-value
Role in assessing FMD			<0.001*
To provide only a diagnosis	15(3%)	6 (0.9%)	
secure expert management	262(52%)	239 (37.7%)	
coordinate interdisciplinary long-term management	202(40%)	358 (56.5%)	
diagnosis and manage personally	25(5%)	31 (4.9%)	
Role of Electrophysiology			0.002*
do not have access	121(24%)	210 (33.1%)	
do not think electrophysiology is useful	45(9%)	43 (6.8%)	
Discussion of Electrophysiology results			<0.001*
Never/rarely	202(40%)	193 (30.5%)	
Sometimes	196(39%)	176(27.8%)	
Often/always	106(21%)	265(21.2%)	
Necessary for clinical definite diagnosis of FMD			
emotional disturbance	88(17.5%)	73 (11.5%)	0.005*
psychiatric disturbance	38(7.5%)	75 (11.8%)	0.017*
multiple somatizations	111(22%)	119 (18.8%)	0.182
functional signs on neurological exam	358(71%)	495 (78.1%)	0.007*
Incongruent exam	361(71.6%)	385 (60.7%)	<0.001*
inconsistent exam over time	285(56.5%)	327 (51.6%)	0.106
Use of Suggestions			<0.001*
Never/rarely	128 (19%)	150 (23.7%)	
Sometimes	158(34%)	211 (33.3%)	
Often	139(30%)	194 (30.6%)	
Always	79(17%)	79 (12.5%)	
Use of Placebo			0.720
Never/rarely	378 (75%)	468 (73.8%)	
Sometimes	N/A	110 (17.4%)	
Often	N/A	49 (7.7%)	
Always	N/A	7 (1.1%)	



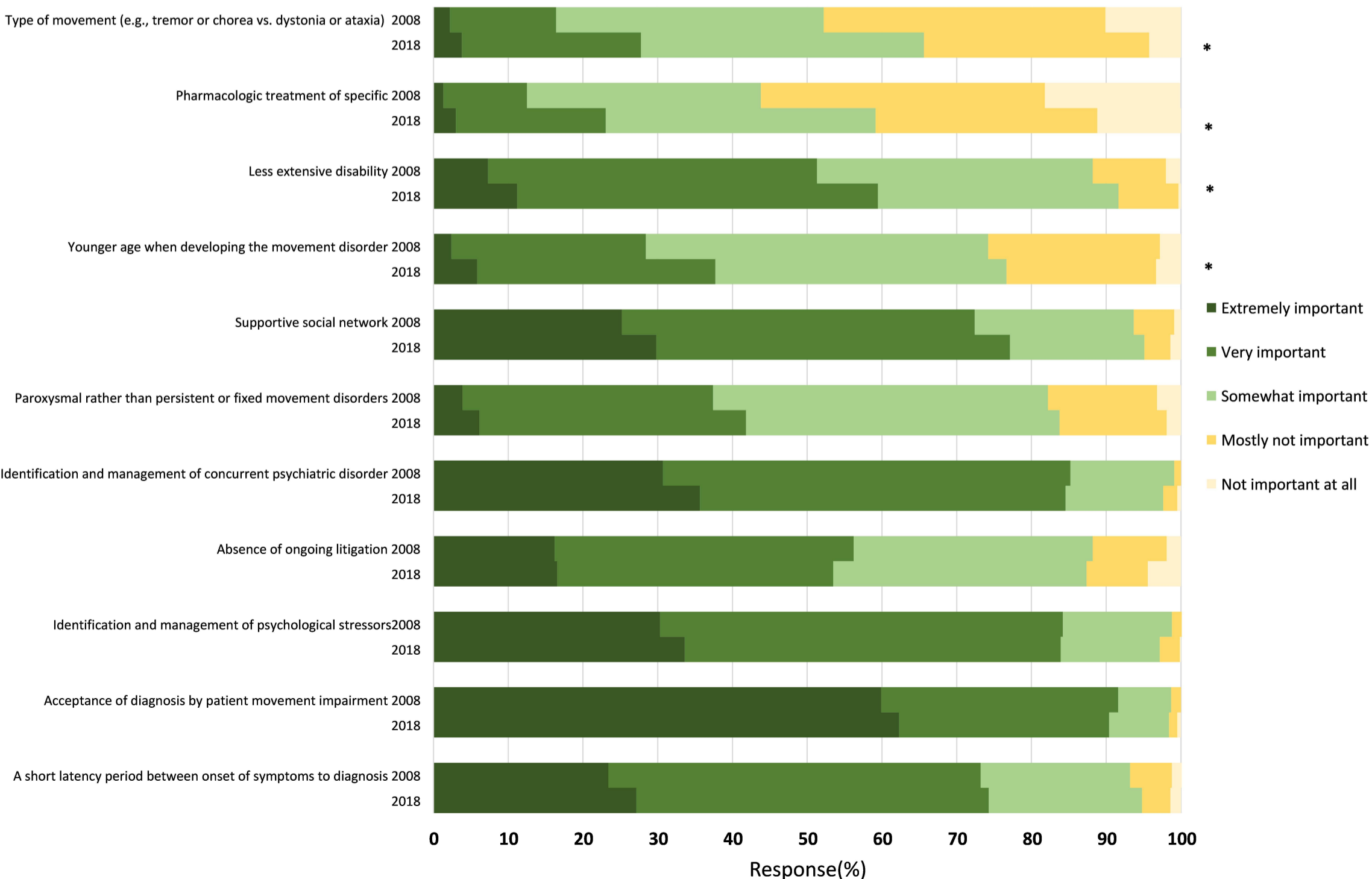
Opinion on effectiveness of specific treatment strategies

2A



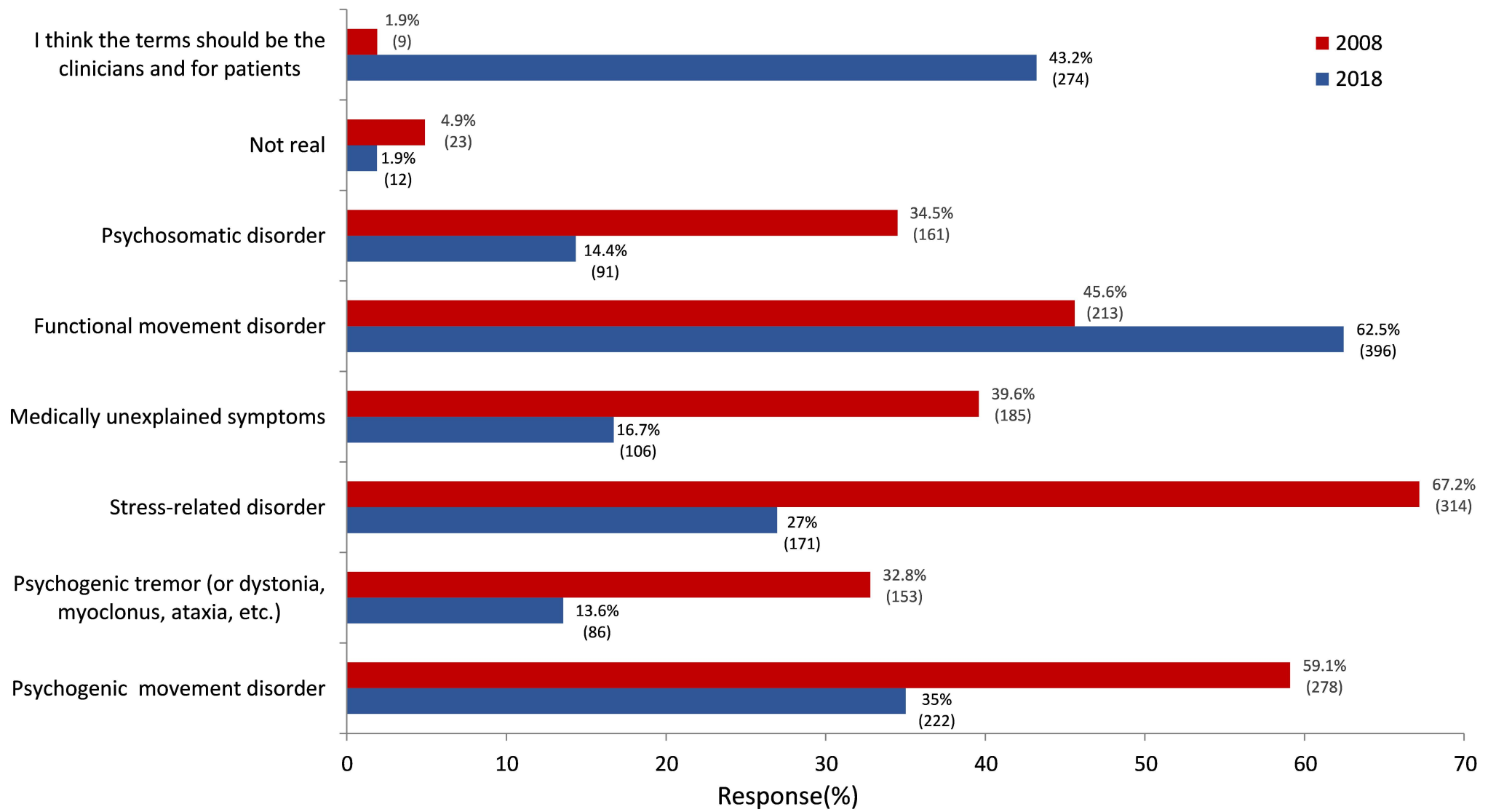
2B

Importance of various factors in predicting a better prognosis of FMD



3A

Preferred lay terms



3B

Preferred medical terms

