

Primary care physicians' perceptions of the challenges and barriers in the timely diagnosis, treatment and management of fibromyalgia

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OBJECTIVES: To describe beliefs and practice patterns of primary care physicians (PCPs) providing fibromyalgia (FM) care, and to characterize differences between PCPs who report being able to provide timely and beneficial care versus the remaining PCPs.

METHODS: A mixed-methods approach including surveys followed by semi-structured focus groups among United States-based PCPs in seven cities was used. Post hoc, a composite threshold of timely and beneficial care, defined as PCPs reports of at least one-half of their patients achieving an 'acceptable' quality of life within one to four office visits after diagnosis, was created to compare subgroups.

RESULTS: Forty-six per cent of PCPs reported some uncertainty when diagnosing FM. PCPs reported personally treating approximately two-thirds of their patients (63%), and reported an average of three dosage titrations. In a post hoc exploratory analysis, 42.5% of PCPs met a composite threshold of self-reported timely and beneficial FM care. These PCPs reported fewer office visits to confirm an FM diagnosis (2.7 versus 4.0 visits [$P<0.01$]) and more patients with 'significant improvement' (38% versus 23% [$P<0.01$]) after six months of treatment compared with the remaining PCPs.

CONCLUSIONS: Physicians self-reported an inadequacy in diagnosing, treating and managing patients with FM in current practice. A subset of PCPs, however, perceived an ability to reach a definitive diagnosis and initiate treatment plans relatively sooner than the other respondents. If the perception of this subset can be confirmed with objective clinical outcomes, and these behaviours modelled, steps could be taken to improve FM care within the broader PCP setting.

Key Words: *Diagnosis; Fibromyalgia, Focus group; Practice patterns; Primary care physicians; Survey; Treatment*

Fibromyalgia (FM) is a complex, multifaceted disorder characterized by widespread bodily pain, chronic fatigue, sleep deprivation and psychosocial distress. Currently affecting between 2% and 4% of the United States (US) population, FM represents a significant source of physical and cognitive disability (1-4). Since FM was officially classified in 1990, researchers and clinicians have struggled to decipher its etiology and manage its diverse symptoms efficiently (5). While some practitioners view FM as a distinct chronic pain condition, other clinicians have difficulty accepting FM as a valid medical disorder (6).

Recommendations from the American College of Rheumatology, the American Pain Society and the European League against Rheumatism have yet to be codified into a standard set of criteria and practice algorithms (2,7,8). Thus, without expert consensus, physicians must rely on individual experience when developing treatment regimens for FM patients that may delay optimal care (9). Unlike well-defined pain conditions, such as rheumatoid arthritis and Sjögren syndrome, FM may be particularly challenging in the primary care setting due to the lack of diagnostic and treatment algorithms.

Les perceptions des défis et des obstacles dans le diagnostic, le traitement et la prise en charge rapides de la fibromyalgie par les médecins de première ligne

OBJECTIFS : Décrire les croyances et les profils de pratique des médecins de première ligne (MPL) qui fournissent des soins en fibromyalgie (FM) et caractériser les différences entre les MPL qui déclarent pouvoir fournir des soins rapides et bénéfiques et les autres MPL.

MÉTHODOLOGIE : Les chercheurs ont adopté une méthodologie mixte incluant des sondages suivis de groupes de travail semi-structurés chez des MPL provenant de sept villes des États-Unis. Pour comparer les sous-groupes, ils ont ensuite créé un seuil composite de soins rapides et bénéfiques, définis comme la déclaration des MPL indiquant qu'au moins la moitié de leurs patients étaient parvenus à une qualité de vie « acceptable » au bout de une à quatre visites en cabinet après le diagnostic.

RÉSULTATS : Quarante-six pour cent des MPL ont déclaré une certaine incertitude lorsqu'ils diagnostiquent une FM. Les MPL ont déclaré traiter personnellement environ les deux tiers de leurs patients (63 %) et effectuer une moyenne de trois titrages de posologie. Dans une analyse exploratoire *a posteriori*, 42,5 % des MPL ont respecté un seuil composite de soins rapides et bénéfiques de la FM. Ces MPL ont déclaré moins de visites en cabinet pour confirmer un diagnostic de FM (2,7 par rapport à 4,0 [$P<0,01$]) et plus de patients qui présentaient une « amélioration importante » (38 % par rapport à 23 % [$P<0,01$]) six mois après le traitement par rapport aux autres MPL.

CONCLUSIONS : Les médecins ont eux-mêmes déclaré une incapacité à diagnostiquer, à traiter et à prendre en charge les patients ayant une FM dans leur pratique. Un sous-groupe de MPL a toutefois perçu une capacité de parvenir à un diagnostic définitif et à amorcer un plan thérapeutique relativement plus vite que les autres répondants. Si la perception de ce sous-groupe peut être confirmée par des issues cliniques objectives et si ces comportements peuvent être transformés en modèles, on pourra prendre des mesures pour améliorer les soins de la FM par l'ensemble des MPL.

Research has indicated that it takes an average of five years for a patient to be diagnosed with FM (9), and patients are often dissatisfied with their provider-recommended course of therapy, despite expectations that treatment will yield substantial improvement (10). Furthermore, although FM is the second most common disorder rheumatologists encounter in clinical practice, US rheumatologists currently provide care for <20% of FM patients. Instead, primary care physicians (PCPs) are the front line of care, attempting the first differential diagnoses of FM and initial treatment strategies (11-14).

We hypothesized that significant unmet needs regarding the timely and satisfactory diagnosis, management and treatment of FM would be evident, even when measured as physicians' self-report. Our research set out to describe the challenges faced and approaches taken by PCPs in the diagnosis, management and treatment of FM. To the best of our knowledge, no validated model of PCP perceptions or attitudes toward FM has been published that describes or predicts timely and beneficial care to patients. Therefore, a secondary objective of the present research was to introduce the concept of timely and beneficial care,

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and to define it using a combination of survey responses designed to identify PCPs who self-report being able to provide such timely and beneficial care to their FM patients.

METHODS

Study design

A hybrid qualitative-quantitative research methodology was used to address these study objectives. Focus groups were used to assess qualitatively physician attitudes and perceptions about FM. In addition, physicians were asked to complete short surveys at the focus group centre to quantitatively capture their practice characteristics, treatment approaches and patient management experiences.

Recruitment sample

US-based physicians from seven cities (Atlanta, Boston, Chicago, Dallas, Denver, Phoenix and San Francisco) were recruited using physician panels provided by the focus group facility. To qualify for the study, physicians were screened using the following criteria: must be in family/general primary care practice and internal medicine; must be board-certified or board-eligible; must manage a caseload of 300 or more adult patients per month; must have been practising between one and 30 years since residency; must spend at least 50% of professional time in direct patient care; and, if in a private practice or office-based setting, must spend at least 50% of professional time in that setting. Physicians were excluded from participating if they had participated in market research on chronic pain in the previous three months, held a consulting relationship with or received funding from any pharmaceutical company, and/or did not agree that "fibromyalgia is a 'real' condition" (ie, rated <4 on a 1 to 7 point scale in which 1 = 'disagree completely' and 7 = 'agree completely').

A single agency that offers a chain of focus group facilities (Fieldwork Inc, USA) recruited the physicians and also hosted the group discussions. Recruiting lists were developed and maintained by Fieldwork Inc based on physician proximity to the focus group facility (area zip codes) and physician referrals. During the recruiting process, PCPs were informed that they would be discussing FM with other PCPs in a focus group setting.

Data collection/instruments

Two PCP focus groups were conducted in each of the seven US cities (total of 14 focus groups and survey sessions) between September and October 2009. Before each focus group, respondents were asked to complete a survey. Moderated using a structured discussion guide, focus group sessions lasted for 75 min to 100 min depending on the size of the group and the degree of discussion. The survey took approximately 15 min to 20 min to complete. One of four centrally trained senior members of the study team moderated each focus group. The guide included topic areas relating to physician beliefs, attitudes and practices in the care of patients with FM, specifically relating to assessment, diagnosis, treatment and patient management. PCPs were asked to focus only on patients they had treated and not to speculate on those they had referred to specialists. Survey and discussion guide contents were developed in collaboration with two expert clinician advisors (rheumatologist and family medicine physician). The survey included a set of closed-ended questions on practice and patient characteristics, and office visits as they related to confirming a diagnosis of FM, differential diagnoses, treatment and outcomes.

Statistical analyses

Continuous variables were summarized as mean, median, SD and range. Categorical variables were described as proportions of responders. In a post hoc analysis, an exploratory composite index was created of PCP perception of timely and beneficial care as measured by two survey questions. PCPs were asked to recall the number of office visits typically required until their FM treatment plan resulted in a patient reporting an 'acceptable' quality of life (QoL). PCPs were next asked

TABLE 1
Primary care physician (PCP) practice and patient caseload characteristics

Characteristic	All PCPs (n=94)
Sex	
Male	86
Female	14
Specialty	
Family/general practitioners	43
Internists	57
Patient caseload per month (including new and existing patients), n (range)	429 (300–800)
Patients with chronic pain in four quadrants, % (range)	17 (2–60)
Patients with primary fibromyalgia, % (range)	5 (0–23)

Data presented as % unless otherwise indicated

to estimate what proportion of their patients achieved an 'acceptable' QoL, as deemed by the patient or PCP, at each office visit (ie, visit 1, visit 2, visit 3, etc). For this analysis, therefore, PCP responses were categorized into those who reported being able to achieve acceptable QoL for $\geq 50\%$ of their FM patients in one to four visits (achieved or met index), and the control group (did not meet index). The four-visit threshold was established because it approximated the average number of office visits needed to reach a definitive diagnosis of FM, as derived from the entire PCP sample population. Student's *t* test for means and χ^2 tests for proportions were used to compare PCP subgroups. Statistical significance was set at $P=0.05$. Survey data were entered and analyzed using SPSS version 18.0 (IBM Corporation, USA). No power testing was performed on these data.

RESULTS

Physician and practice characteristics

Of the total of 2927 physicians contacted, 94 (3.2%) PCPs were eligible for the research based on the screening criterion and willingness to participate. Table 1 summarizes the distribution of the 94 PCPs according to sex, specialty and patient caseload characteristics. The majority of PCPs (92%) worked in private practice, 7% in hospitals and 1% were involved in teaching. The mean period of time in practice since residency was 19 years (range 1 to 32 years). Fifty-four per cent of respondents reported that they feel "very certain" when they diagnose FM, 30% feel "somewhat certain" and 16% stated that they "do not feel very certain" when diagnosing FM.

Assessment and diagnosis

Physicians reported that, before making a diagnosis of FM, they "rule out" more serious conditions. The top five conditions that respondents considered the most important to rule out in the differential diagnosis of FM were hypothyroidism (79%), rheumatoid arthritis (70%), polymyalgia rheumatica (71%), depression (84%) and systemic lupus erythematosus (62%). On average, PCPs required approximately 3.5 office visits (range one to 12 visits) from the time the patient first presented with chronic pain to confirm a diagnosis of FM; mean duration of each visit was 21 min (range 10 min to 45 min). PCPs reported that they were able to diagnose 16% of their patients in the first visit, an additional 28% within two visits, 36% in three to four visits and the remaining 20% in five or more visits.

Treatment

A majority of PCPs (63%) reported that they personally treat their patients after diagnosis, while 37% refer patients to a specialist. Among patients with suspected FM, PCPs reported starting initial pharmacological treatment just before confirmation of the FM diagnosis. Physicians reported that the types of symptoms and complaints they considered important to address with the initial treatment plan were pain (69%), depression (57%), and lifestyle modifications such as

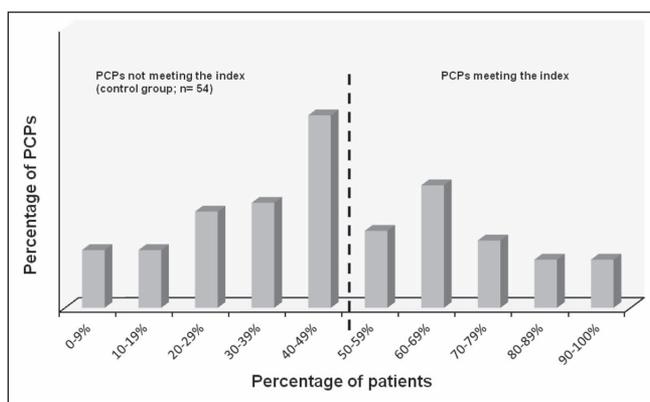


Figure 1 Distribution of fibromyalgia (FM) patients with 'acceptable' quality of life within one to four office visits. Based on survey question: "Think about the number of office visits typically required for you and your FM patients to find the 'right' FM treatment plan for them, defined as therapy that results in patients achieving a quality they deem as 'acceptable'. How would you classify all of your FM patients currently receiving pharmacological treatment across the following series of office visits before a treatment was deemed appropriate and acceptable by either you or your FM patient?" Five office visit categories were provided for respondents to enter patient percentages, including two summed for subgroup creation: '1 to 2 office visits' and '3 to 4 office visits'. PCP Primary care physician

exercise, diet (56%) and sleep (54%). PCPs reported a multimodal approach when developing an initial treatment plan, prescribing the following treatment categories to a high proportion of their patients: pharmacological (73%), over-the-counter (30%) and nonpharmacological (48%) therapies including counselling, pain management, physical therapy, lifestyle modification and alternative medicine. The pharmacological therapies that PCPs reported prescribing first were nonsteroidal anti-inflammatory drugs (NSAIDs) (54%), anticonvulsants (51%), muscle relaxants (50%), tricyclic antidepressants (TCAs) (44%) and sedatives (32%). After the initial treatment plan, PCPs recalled that their typical modification might include an increase in anticonvulsants (88%), serotonin and norepinephrine reuptake inhibitors (89%) and selective serotonin reuptake inhibitors (54%), but a decrease in sedatives (57%), muscle relaxants (44%) and TCAs (43%). PCPs reported an average number of three drug modifications or dosage titrations (range 0 to 10 titrations) before the patient reported some improvement to the physician.

Patient outcomes and management

PCPs reported on the outcomes they believed were most relevant to their FM patients. The top four responses were QoL (88%), activities of daily living (80%), level of pain (visual analogue scale) (69%) and physical mobility/function (66%). PCPs characterized outcomes for their newly diagnosed FM patients and again for their total caseload of FM patients. After six months of treatment, PCPs reported that they found significant improvement in 29% of their newly diagnosed patients, some improvement in 38%, no change in 23% and worsening symptoms in 10%. Among their full caseload of FM patients, physicians reported that over three-quarters of patients (76%) experienced improvement over time (26% mild, 32% moderate and 18% marked improvement), while the remaining patients either showed no improvement (16%) or were treated too recently to be evaluated (8%).

Exploratory analysis

Less than one-half (42.5%) of PCPs met the post hoc composite index of timely and beneficial care, defined specifically as PCP perception that the majority of their patients (>50%) achieved an 'acceptable' QoL within one to four office visits post diagnosis (Figure 1). Per definition, the mean

TABLE 2
Practice patterns for fibromyalgia (FM) patients according to primary care physician (PCP) subgroups

	PCPs who met index (min-max)	Control group (min-max)
Assessment and confirmation of diagnosis		
Patients referred to specialist, %	28	40
Frequency of office visits [†] , weeks	2.9	2.5
Duration of scheduled visit, min (range)	22 (12–45)	21 (10–45)
Office visits required for diagnosis confirmation, n (range)	2.7** (1.0–5.0)	4.0 (1.0–12)
Patients diagnosed per visit, %		
1–2 visits	56**	34
3–4 visits	32	39
≥5 visits	12**	27
Total time, min	59*	83
Treatment of FM		
Patients referred to specialist, %	31	42
Frequency (range) of office visits, weeks	8.7 (1.1–22)	8.4 (1.1–26)
Office visits per year, n (range)	10.0 (2.4–48)	12.1 (2.0–48)
Duration (range) of scheduled visit [‡] , min	17 (10–30)	19 (10–30)
Office visit when start pharmacological treatment	2.4	3.2
Office visits required to find 'right' treatment	3.8*	4.6
Patients with 'right' treatment per visit after drug treatment initiation, %		
1–2 visits	23**	8.0
3–4 visits	45**	20
5–8 visits	19**	34
≥ 9 visits	6.3**	15
Never	6.1**	22
Total time to find 'right' treatment, min [‡]	65*	89
Number of dosage modifications and new prescriptions before patient improvement	2.5**	3.5
Patient outcomes and management		
Frequency (range) of office visits, weeks	15 (4.3–26)	13.1 (3.7–26)
Office visits per year, n (range)	4.8 (2.0–12)	5.2 (2.0–14)
Duration (range) of scheduled visit, min	17 (10–30)	19 (10–30)
Patient improvement after six months of treatment, %		
Significant improvement	38**	23
Some improvement	39	37
No improvement	16**	28
Worsening symptoms	7.2	12
Patient improvement among all current FM patients, %		
Marked improvement	24**	13
Moderate improvement	36	28
Mild improvement	23	30
No improvement	10**	20
Too soon to tell	7.3	8.3

*P<0.05; **P<0.01. [†]Derived from PCP group ratio of visits in treatment and management phase; [‡]Assumes same office visit duration (min) as that for after the 'right' treatment is identified (patient outcomes and management). 'Right treatment' defined as finding the therapy resulting in patients' achieving a quality of life they deem acceptable. max Maximum; min Minimum

number of patients with physician-perceived acceptable QoL was significantly different between groups (68% and 28%, respectively, P<0.01) (Table 2). Similarly, these physicians reported more newly diagnosed cases with significant improvement (38% versus 23% [P<0.01]) and fewer with no improvement (16% versus 28% [P<0.01]) after six months of treatment compared with the remaining respondents. This pattern also held when prevalent and incident cases were compared between the two groups (marked improvement: 24% versus 13% [P<0.01]).

TABLE 3
Practice characteristics of the two primary care physician (PCP) subgroups

	PCPs who met the index (n=40)	Control group (n=54)
General/family practice	37	46
Internal medicine	63	54
Male	92	81
Female	7.5	19
Years in practice, mean	18	20
Professional time spent in:		
Direct patient care	97	96
Private practice	92	93
Hospital-based office	7.3	6.1
Other (teaching, research, etc)	1.0	1.0
Urban location	33	36
Suburban location	64	64
Rural location	2.6	0

Data presented as % unless otherwise indicated

Physicians who met the composite index reported fewer office visits required to confirm the FM diagnosis (2.7 versus 4.0 visits [$P<0.01$]), with less time to diagnosis (59 min versus 83 min [$P<0.05$]). Furthermore, physicians who met the care composite index made fewer drug or dosage modifications than physicians who did not meet the index (2.5 versus 3.5 modifications [$P<0.01$]). No statistically significant differences were observed between the two PCP subgroups for specific physician or practice characteristics measured in the survey (see Table 3 for PCP and Table 4 for patient caseload characteristics). No significant differences were found in physician reports of when pharmaceuticals were prescribed (2.4 versus 3.2 visits [$P=0.13$]), changes to the initial treatment plan or the duration of scheduled office visits (22 min versus 21 min).

DISCUSSION

Results of the present research suggest that PCPs perceive significant barriers in the diagnosis and treatment of FM in current practice, indicated by the finding that nearly one-half (46%) reported some uncertainty when diagnosing FM. This is consistent, perhaps, with the lack of a standardized diagnostic algorithm. In addition, PCPs perceive themselves as the front line of care, personally treating approximately two-thirds of their FM patients (63%). For incident cases, these PCPs reported widespread use of NSAIDs, anticonvulsants, muscle relaxants, TCAs and sedatives, indicating that symptom relief is the initial priority. No single patient-reported outcome instrument was identified as the standard for monitoring FM. Rather, PCPs reported relying on many different patient-reported instruments, including measures of QoL, activities of daily living, level of pain (visual analogue scale) and physical mobility/function. In spite of such efforts, these same physicians reported that only one-half of their FM caseload experienced moderate or marked improvement. Furthermore, they reported that an average of three drug/dose modifications (range 0 to 10) were necessary before they perceived at least some improvement in the FM patients.

In an exploratory post hoc analysis, we introduced a modest composite category of timely and beneficial care and found that 43% of PCPs met this index, believing that they offered at least one-half of their patients an 'acceptable' QoL within four visits after diagnosis. These physicians also reported less time (as measured by office visit or mean visit time) to determine a diagnosis of FM and ordered fewer dose modifications during the course of patient care compared with those who did not meet the index.

If the perception of this subset of PCPs could be proven objectively, and their practices modelled, the clinical benefits for FM patients would be substantial. In a 2007 retrospective claims analysis (6), the mean number of physician visits over a 12-month period was

TABLE 4
Typical patient caseload per month for primary care physician (PCP) subgroups

	PCPs who met the index (n=40)	Control group (n=54)
All patients seen, mean (median)	430 (400)	429 (400)
Patients with chronic pain in four quadrants, mean (median)	74 (50)	69 (50)
Percentage of all patients seen/month	18	16
Patients with primary FM, mean (median)	22 (10)	20 (15)
Percentage of all patients seen/month	5.1	4.7
Percentage of FM patients with insurance*	91	92
Percentage with private insurance	56	48
Percentage with Medicare/>65 yrs	14	19
Percentage with Medicare/disability	15	16
Percentage with Medicaid	5.6	9.0
Percentage of FM patients without insurance*	9.0	8.1

*PCP sample size for this question: met index, n=39; control, n=51. FM Fibromyalgia; yrs Years of age

four times higher for FM patients compared with controls. Similarly, a 2005 study by White et al (15) determined that FM patients averaged more yearly visits to PCPs (4.8 versus 4.3) compared with controls. Therefore, confirming a diagnosis of FM and implementing a successful treatment regimen in fewer office visits may save money for both the PCP practice and society, especially among capitated managed care plans.

There are several limitations to the present study. The study sample was not a random selection, but rather a convenience sample and may, therefore, be subject to selection and volunteer bias. As such, these results may be difficult to apply to other populations, and we cannot suggest that the physicians in our study were a truly representative sample of all PCPs. The sample size was too small to test for certain differences between PCP subgroups, such as those according to physician sex or age, or to detect small or subtle differences in FM diagnosis and care. Importantly, we recognize that this research only addressed the physician perspective, and was limited to real-time recall of patient and practice information, without the essential collaboration of FM patients or an objective review of medical charts to confirm or refute perceptions. Because PCP impressions of patient improvement were qualitative assessments and not a summation of validated QoL instruments, this outcome may be particularly vulnerable to bias and error.

The present study also did not consider the potential impact of nonphysician providers, affiliated staff and care providers on the diagnosis, treatment and management of FM. Survey questions were, by necessity, kept broad to prompt better physician recall at the expense of some meaningful detail. For example, patients were categorized as either newly diagnosed or as total caseload, and treatments were only described according to drug class. As such, the present study cannot claim to capture comprehensively potential differences in patient characteristics across different physician practices, and the possibility that our findings may be a result of differences in patient populations, rather than in PCP practices, cannot be ruled out. Finally, the present pilot study was not designed to analyze specific PCP treatment patterns or details of patient management, but to explore broad self-reported themes that may be useful in identifying better FM care.

Our composite index is a simple partitioning of PCPs into comparison groups to test for differences in responses to survey questions and is only a modest first step toward the development of a clinically valid

treatment algorithm. We encourage further research to understand the impact of initial treatment selection and subsequent treatment modifications on clinical outcomes in FM, and hope this work will spur further, more detailed, treatment-oriented research and model construction.

SUMMARY

This research suggests that physicians self-report inadequacies in the diagnosis and treatment of FM patients in current practice, a significant finding that deserves acknowledgement and follow up study. This research also suggests that some physicians are utilizing methods that allow them to achieve desirable effects quickly and for a majority of their patients. Further research is needed to identify and validate specific treatment practices that would lead to more timely and beneficial care of FM patients, and to assess ways to overcome the challenges currently perceived by PCPs.

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