ARTHRITIS & RHEUMATISM
Vol. 54, No. 1, January 2006, pp 177–183
DOI 10.1002/art.21545

The Impact of a Diagnosis of Fibromyalgia on Health Care Resource Use by Primary Care Patients in the UK

An Observational Study Based on Clinical Practice

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Objective. **To investigate the impact of a diagnosis of fibromyalgia (FM) in clinical practice on health care resource use in the UK.**

Methods. **Rates of visits, prescriptions, referral, and diagnostic testing were estimated in patients who had been diagnosed as having FM between 1998 and March 2003 in UK primary care and compared with those in matched controls. Rates were calculated in 6-month intervals from 10 years before until 4 years after the FM diagnosis.**

Results. **Patients (2,260) were newly diagnosed as having FM; 81.3% were women. Their mean age was 49 years. FM patients had considerably higher rates of visits, prescriptions, and testing from at least 10 years prior to diagnosis compared with controls. By the time of diagnosis, FM patients had 25 visits and 11 prescriptions per year compared with 12 visits and 4.5 prescriptions per year in controls. Visit rates were highest for depression, followed by fatigue, chest pain, headache, and sleep disturbance. Following diagnosis, visits for most symptoms and health care use markers declined, but within 2–3 years, most visits rose to levels at or higher than those at diagnosis.**

Conclusion. **Primary care patients who had been diagnosed as having FM reported higher rates of illness and health care resource use for at least 10 years prior to their diagnosis, which suggests that illness behavior may play a role. Being diagnosed as having FM may help patients cope with some symptoms, but the diagnosis has a limited impact on health care resource use in the longer term, possibly because there is little effective treatment.**

Fibromyalgia (FM) is a disorder in which patients complain of a generalized ache of the body. Upon examination, areas of focal tenderness, called tender points, have been demonstrated in characteristic locations (1–3). A broad range of other symptoms is often present and includes fatigue, morning stiffness, sleep disturbance, depression, irritable bowel syndrome (IBS), chest pain, and headaches (1,4). Controlled studies have shown that amitriptyline (5,6), cyclobenzaprine (7), alprazolam (8), aerobic exercise (9), and other interventions may be useful in treating FM, but the proportion of patients who respond to each intervention alone is small. Psychological treatment and physical therapy may be more effective for patients than pharmacologic treatment (10).

There is little doubt that FM is associated with significant societal and health care costs (11–16). Patients with FM may repeatedly present to the general practitioner with various symptoms before a definitive diagnosis of FM is made. As a result, general practitioners may be more likely to diagnose FM in patients who frequently present with symptoms related to FM, while patients who meet the diagnostic criteria but who rarely present at the practice may be missed. But there are few data on whether the act of diagnosis actually compounds the problem (17). The condition is of unknown etiology, and this, together with the lack of verifiable diagnostic criteria, has led some to speculate

Supported by Pierre Fabre SA, France.
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Submitted for publication November 30, 2004; accepted in revised form October 6, 2005.

that it does not exist (18) or is at best a surrogate marker for underlying psychosocial problems (19,20). As such, the very process of diagnosing a patient with FM may exacerbate symptoms and lead to increased dependence on health care providers (18–22). The one study that addressed this issue found a slight reduction in health care resource use and FM-related symptoms at 36 months after the diagnosis, although only 43 of the original 72 newly diagnosed patients remained at followup (23).

In this study, we examined diagnoses of FM made in "real-life" clinical practice and recorded by general practitioners in a large primary care population in the UK. We investigated the impact of the diagnosis on the frequency of visits for a spectrum of symptoms and on the use of health care resources.

PATIENTS AND METHODS

Data source. The Full Feature General Practice Research Database (FF-GPRD) is a collection of electronic medical records of patients who have attended >350 general practices in the UK, and represents ~4.6% of the UK population. FF-GPRD is a computerized database of longitudinal records from primary care clinics and contains a unique encrypted patient identification number, demographic information, list of prescriptions, medical symptoms and diagnoses, referrals, and dates of registration and transferring out of the general practices (24).

Study population. All patients in the FF-GPRD with a recorded diagnosis of FM in their electronic record from January 1, 1998, and who were registered at the practice for at least 2 years prior to their first diagnosis of FM, were identified as FM cases. The date of FM diagnosis was defined as the index date. The prevalence of FM was estimated by dividing the number of FM cases by the total number of patients in the FF-GPRD population. Once a patient had been diagnosed as having FM, he or she was assumed to be a prevalent case up to the point at which he or she transferred out of the database.

A non-FM control group (with 10 controls per case) was generated by matching subjects for index date, practice, sex, and year of birth. (An unmatched control group was also generated, but since the findings were similar for both control groups, only data for the matched control group are presented in this study.)

Diagnoses of FM were identified by careful review of the Read medical codes and Oxford Medical Information System (OXMIS) medical codes in the patient's electronic record, and only specific diagnoses were included (Table 1). Diagnoses of fibrositis were excluded. The Read and OXMIS medical codes are part of a mandatory medical terminology coding system for use in primary care in the UK. Each term identifies a symptom, sign, or diagnosis clinical concept (which may be described by >1 term). OXMIS codes preceded Read codes and were used until the late 1990s. Read codes are based on codes in the International Classification of Diseases, Ninth Revision.

Table 1. Read and OXMIS medical codes and terms used by general practitioners to define fibromyalgia in the GPRD*

Read/OXMIS term	Read/OXMIS code
Fibromyalgia	N248.00
Fibromyalgia	N239.00
Fibromyositis NOS	N241200
FIBROMYALGIA	7339F

* OXMIS = Oxford Medical Information System; GPRD = General Practice Research Database; NOS = not otherwise specified.

Definitions. The following definitions are used throughout this article. Visit is defined as a patient's visit to the general practitioner (known as a consultation in the UK). It may refer to all visits or to those for specific clinical outcomes. Referral is defined as referral of the patient to a secondary care specialist by the general practitioner. Test is defined as all laboratory tests requested by the general practitioner. Prescription is defined as a prescription for a drug or therapy issued to the patient by the general practitioner.

Rate of clinical, therapeutic, and health service outcomes. Rates per 100 person-years (with 95% confidence intervals) of the clinical, therapeutic, and health service outcomes of interest were estimated in 6-month intervals for up to 10 years before and up to 4 years after the index date by dividing the total number of events by the total exposure time for the respective patient cohort.

The analysis was performed for the following groups of events. 1) Diagnosis-related procedures: (a) total number of referrals to secondary care specialists, stratified by referral to rheumatologists and all other referrals, and (b) total number of tests requested by the general practitioner. 2) All patient visits to the general practitioner (i.e., patient encounters with the general practitioner), and visits for the following specific clinical symptoms: depression, IBS, fatigue, sleep disturbance, chest pain, headache (excluding migraine), migraine, dizziness, "heightened sensitivity, numbness, and tingling sensations," facial pain, "dry eyes, skin, and mouth," mood changes, painful menstrual periods in women, pelvic pain in women, poor concentration, and irritable bladder. Diagnoses were identified by careful review of Read and OXMIS diagnostic terms held in the database. No specific terms could be identified for generalized muscle pain and stiffness. 3) Total number of prescriptions, and the following specific prescriptions: nonsteroidal antiinflammatory drugs (NSAIDs), tricyclic antidepressants, and selective serotonin reuptake inhibitors (SSRIs). Systemic corticosteroids were not analyzed due to insufficient data.

When calculating rates of the selected clinical outcomes, the analysis included repeat visits by patients for the same outcome. Therefore, the analysis gives the rate of all visits for each outcome, not the incidence (although for outcomes characterized by short, acute episodes such as headache, the rate of visits approximates the incidence). For each clinical outcome, referral, and total number of visits, only 1 episode per patient per day was included in the analysis. (While it was possible that a patient may have been referred to >1 specialist on a given day, the frequency was small [<1%]. Because patients would not be referred to a rheumatologist more than once on a given day, the analysis of the entire

Table 2. New FM diagnoses recorded in the GPRD between 1998 and March 2003, stratified by age group and sex*

Sex, age group	No. of cases	% of total cases
Female		
0–9 years	0	0.0
10–19 years	25	1.1
20–29 years	95	4.2
30–39 years	315	13.9
40–49 years	512	22.7
50–59 years	528	23.4
60–69 years	232	10.3
70–79 years	104	4.6
80–95 years	24	1.1
>95 years	0	0.0
Total	1,835	81.3
Male		
0–9 years	0	0.0
10–19 years	5	0.2
20–29 years	24	1.1
30–39 years	86	3.8
40–49 years	109	4.8
50–59 years	102	4.5
60–69 years	62	2.7
70–79 years	28	1.2
80–95 years	9	0.4
>95	0	0.0
Total	425	18.7
Total cases	2,260	100.0

* FM = fibromyalgia; GPRD = General Practice Research Database.

referral data set applied this restriction.) However, for the analysis of prescriptions and tests, multiple episodes per patient per day were permitted.

All analyses were performed using Stata 8 software (Stata, College Station, TX). The study was given prior approval by the GPRD Scientific and Ethical Advisory Group.

RESULTS

Description of FM cases. Diagnoses of FM have appeared sporadically in the GPRD since 1990 and have become more frequently recorded in practices throughout the UK since about 1996. Between 1998 and the end of March 2003, there were 2,260 new diagnoses of FM recorded in the GPRD (2,257 cases were labeled "fibromyalgia" and 3 cases were labeled "fibromyositis not otherwise specified") (Table 1). There was no clear trend in the rate of diagnosis during this period. Of the 2,260 diagnoses, >70% were in women between 30 and 69 years of age (Table 2). Case age ranged between 10 and 91 years. The mean case age was 49 years, both in women and in men. The prevalence of recorded FM diagnoses was 0.18% overall, and peaked at 0.73% in 50–59-year-old women in 2000. Diagnoses were made in 68% of general practices overall, but there was some regional variation. A diagnosis of FM was more common in practices in Northern Ireland and North West England and was less common in those in Scotland and London.

Clinical visits. Total visit rates were considerably higher in FM cases compared with matched controls for at least 10 years prior to diagnosis, and rose particularly sharply from 3 years prior to diagnosis, to 2,500 visits per 100 person-years (Figure 1A). Thereafter, visits declined slightly but appeared to resurge between 2.5 and 3 years following the diagnosis.

Rates of visits for all of the specific conditions investigated were elevated in cases compared with controls. The most common reasons for visits in FM cases

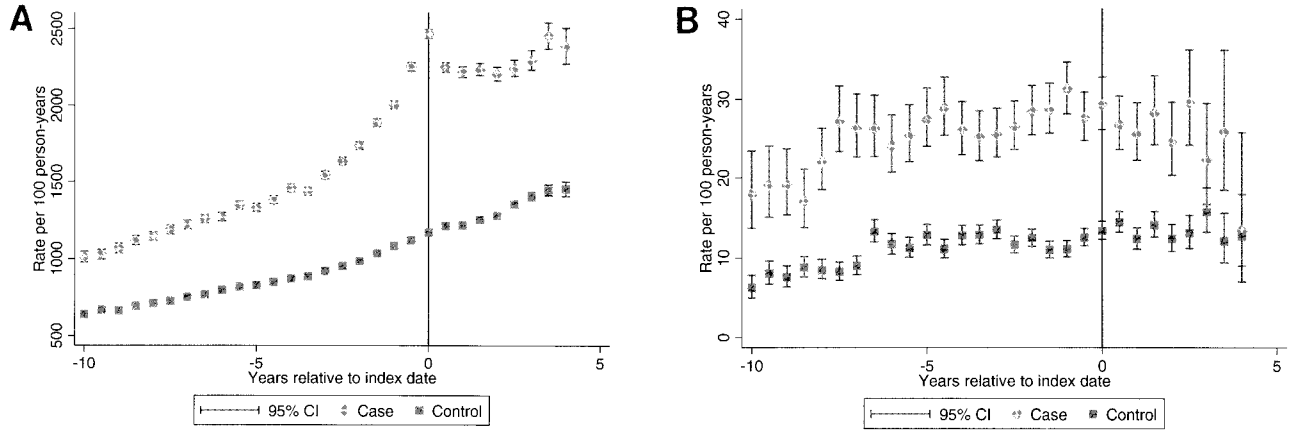

Figure 1. Rate of clinical visits. **A,** Total rate of visits to a general practice by fibromyalgia (FM) cases and by matched controls. **B,** Rate of visits due to depression by FM cases and by matched controls. The vertical line at 0 indicates the date of FM diagnosis in cases and the equivalent matched date (index date) in controls. 95% CI = 95% confidence interval.

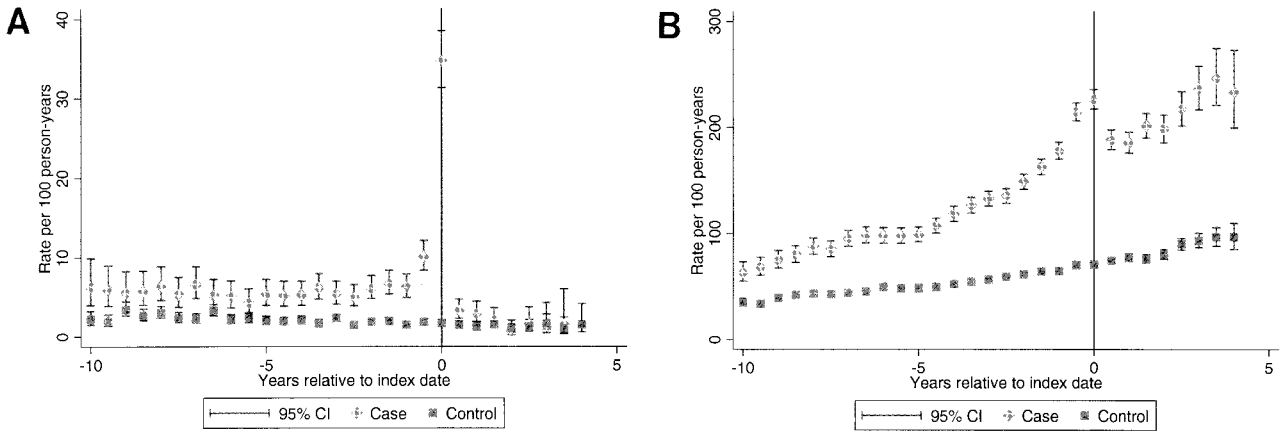

Figure 2. Rate of prescriptions. **A,** Rate of prescriptions of tricyclic antidepressants for fibromyalgia (FM) cases and for matched controls. **B,** Rate of prescriptions of nonsteroidal antiinflammatory drugs for FM cases and for matched controls. The vertical line at 0 indicates the date of FM diagnosis in cases and the equivalent matched date (index date) in controls. 95% CI = 95% confidence interval.

were depression (28 visits per 100 person-years at 6 months prior to diagnosis), fatigue (18 visits per 100 person-years), chest pain (16 visits per 100 person-years), headache (11 visits per 100 person-years), sleep disturbance (10 visits per 100 person-years), dizziness (7 visits per 100 person-years), and IBS (5 visits per 100 person-years). For all other symptoms investigated, there were 5 or fewer visits per 100 person-years in the 6 months prior to diagnosis. The rate of visits for depression by cases rose from 18 to 28 visits per 100 person-years in the 10 years up to FM diagnosis, compared with 6 to 13 visits per 100 person-years by matched controls (Figure 1B). Following the diagnosis of FM, the rate of visits for depression stabilized and then gradually declined during the 4-year followup period after FM diagnosis. A broadly similar pattern of visits was observed for IBS (data not shown). Rates of visits for fatigue rose particularly sharply 3 years prior to the FM diagnosis, to 18 visits per 100 person-years (data not shown). Thereafter, rates dropped and fluctuated at ~10 visits per 100 person-years during the 4-year followup period.

In contrast, visits for sleep disturbance rose steadily from ~5 years prior to FM diagnosis (5 visits per 100 person-years) and continued to do so following FM diagnosis, reaching between 8 and 11 visits per 100 person-years (data not shown). Visits for headache, chest pain, pelvic pain, dizziness, "heightened sensitivity, numbness, or tingling sensations," facial pain, and "dry eyes, skin, or mouth," which had mostly stabilized or dropped immediately following diagnosis, began a steady increase by 2–3 years after FM diagnosis (data not shown). The rate of visits for dysmenorrhea was higher in cases, but declined both in cases and controls prior to the index date.

Prescriptions. Overall rates of prescriptions were significantly higher in FM cases compared with controls (at 6 months prior to FM diagnosis, 1,100 prescriptions per 100 person-years in FM cases compared with 450 prescriptions per 100 person-years in controls) (data not shown). Rates appeared to stabilize for ~3 years thereafter and then continued to rise.

One year prior to FM diagnosis, rates of prescription for tricyclic antidepressants rose sharply in cases and peaked at 35 prescriptions per 100 person-years at diagnosis (compared with 2 prescriptions per 100 person-years in controls). Thereafter, prescriptions for tricyclic antidepressants declined sharply to control levels (Figure 2A). Prescription patterns for SSRIs were similar but less pronounced (data not shown). Rates of prescriptions for NSAIDs rose steadily from 10 years prior to FM diagnosis and, following a brief dip, continued to rise (to 250 prescriptions per 100 person-years) by 4 years after FM diagnosis (Figure 2B).

Diagnosis-related procedures. Overall rates of referral were significantly higher in FM cases compared with controls (at 6 months prior to FM diagnosis, 29 per 100 person-years in FM cases compared with 1 per 100 person-years in controls for referrals to rheumatologists, 130 per 100 person-years in FM cases compared with 57 per 100 person-years in controls for all other referrals to secondary care specialists). Following FM diagnosis, referral rates declined considerably. Referrals to rheu-

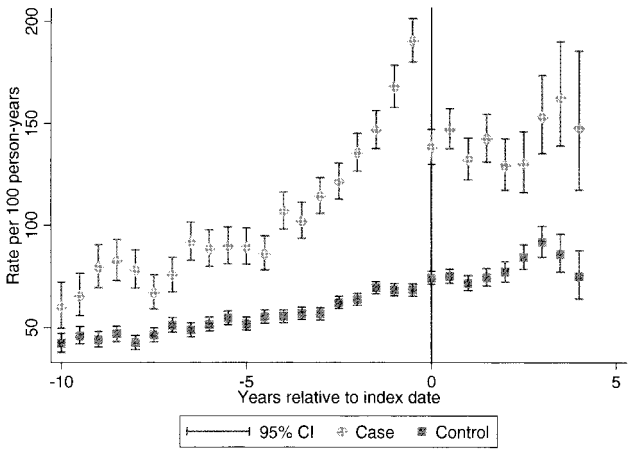

Figure 3. Rate of diagnostic testing. The vertical line at 0 indicates the date of fibromyalgia diagnosis in cases and the equivalent matched date (index date) in controls. 95% CI = 95% confidence interval.

matologists dropped to near the control levels by 4 years following FM diagnosis (data not shown).

Overall rates of diagnostic tests performed were significantly higher in FM cases compared with controls (at 6 months prior to FM diagnosis, 190 tests per 100 person-years in FM cases compared with 68 tests per 100 person-years in controls). Following FM diagnosis, rates of testing dropped slightly and appeared to stabilize for several years (Figure 3). By 3 years following FM diagnosis, testing rates began to rise again.

DISCUSSION

To our knowledge, this is the first observational study to investigate the impact of "real-life" diagnoses of FM in clinical practice. Our study confirms that FM is predominantly diagnosed in women in late middle age and shows that it is associated with high rates of health care resource use and visits for a broad range of conditions for at least 10 years prior to diagnosis. At diagnosis, FM patients had 25 visits per year, compared with 12 visits per year in controls matched for age, sex, practice, and date of FM diagnosis. Increased reporting of illness well in advance of established chronic disease has also been demonstrated in chronic fatigue syndrome and may suggest an illness behavior disorder and/or overlapping illness constructs (25–27). Health care–seeking behavior in FM patients is probably linked with various psychosocial characteristics as well as previous abuse and trauma (28–30). We chose to investigate illnesses considered to be symptoms of FM (4), but which are not included in the American College of Rheumatology (ACR) classification criteria and have been described as epiphenomena with no organic cause (18,20,31). In our study, rates of dysmenorrhea were much higher in cases compared with controls, even though the majority of female cases were menopausal when the FM diagnosis was made.

Despite this, the decline in visits for depression, IBS, and fatigue following diagnosis and for several years thereafter suggests that a diagnosis of FM may be associated with some societal and health care cost benefits. A definitive diagnosis may reassure patients that their symptoms do not reflect a more serious underlying condition. It may allow them to feel more in control (32), which thereby fosters acceptance and allows symptoms to be appropriately treated (23). Simply "being believed" by the medical profession may have a significant influence on patient health and well-being (33–36). In this study, we did not attempt to measure patients' self-determined quality of life. Clearly, if patients are more satisfied with their quality of health following a diagnosis, then this should be taken into consideration when assessing the value of diagnosis.

However, improvements in symptoms may be comparatively short lived. Between 2 and 3 years following the diagnosis of FM, total rates of visits, prescriptions, and testing had risen to levels comparable with those at diagnosis. Furthermore, total rates after diagnosis never fell below the levels achieved 2 years prior to diagnosis. Particularly sharp increases in prescribing, testing, referrals, and visit rates in the 3 years leading up to the diagnosis of FM likely reflect heightened diagnostic investigations with worsening symptoms. Such an effect would be expected prior to the diagnosis of any disease or syndrome. While we did not observe any symptom magnification following the diagnosis of FM, expected by some investigators (18,19), the overall benefit of the diagnostic process remains questionable because there is little to suggest that current treatment is effective in the long term.

The prevalence of diagnosed FM in the GPRD population was considerably lower than that reported in other studies (21,33). Data in the GPRD may reflect the more severe cases being diagnosed by general practitioners, as opposed to cases identified by specific community screening or surveys for FM based on the standard ACR criteria. It is also possible that many general practitioners are reluctant to diagnose conditions that are poorly defined or incompletely medicated (37). Almost one-third of practitioners in this study did not record any diagnosis (irrespective of their registered patient numbers), which suggests that there is practi-

tioner variation in the use of the diagnostic label of "fibromyalgia." Further, the specificity of those diagnoses that are made may be questionable, since only 6% of a sample of British Society for Rheumatology members had adopted the ACR criteria for disease classification (38).

Because this was an observational cohort study, we were unable to obtain results of clinical investigations, including visits for muscle pain, stiffness, or tender points, which may be the most common symptoms on which the diagnosis was based, and possibly those most affected by the diagnosis. Our study design restricted our analysis to patients who had an FM diagnosis recorded by the general practitioner, and it was not possible for us to validate this diagnosis. Some patients may have met the ACR diagnostic criteria but remained undiagnosed because they consulted the general practitioner less frequently than those who were diagnosed. This, combined with evidence of some practitioner variation in diagnosis rates, suggests that our findings may focus on particular patient and practice subgroups. However, this does not affect the primary aim of this study, which was to assess the impact on health care resource use of those patients who are given the diagnostic label "fibromyalgia" in real life. Our study suggests that the high level of health care resource use observed in these patients is, in the longer term, sustained after such a diagnosis is made.

ACKNOWLEDGMENTS

We are grateful to Anthony Brady and Stephan Rietbrock for helpful comments on the analysis.

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