

Prevalence of Fibromyalgia: A Population-Based Study in Olmsted County, Minnesota, Utilizing the Rochester Epidemiology Project

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Objective. To estimate and compare the prevalence of fibromyalgia by 2 different methods in Olmsted County, Minnesota.

Methods. The first method was a retrospective review of medical records of potential cases of fibromyalgia in Olmsted County using the Rochester Epidemiology Project (from January 1, 2005, to December 31, 2009) to estimate the prevalence of diagnosed fibromyalgia in clinical practice. The second method was a random survey of adults in Olmsted County using the fibromyalgia research survey criteria to estimate the percentage of responders who met the fibromyalgia research survey criteria.

Results. Of the 3,410 potential patients identified by the first method, 1,115 had a fibromyalgia diagnosis documented in the medical record by a health care provider. The age- and sex-adjusted prevalence of diagnosed fibromyalgia by this method was 1.1%. By the second method, of the 2,994 people who received the survey by mail, 830 (27.6%) responded and 44 (5.3%) met the fibromyalgia research survey criteria. The age- and sex-adjusted prevalence of fibromyalgia in the general population of Olmsted County by this method was estimated at 6.4%.

Conclusion. To the best of our knowledge, this is the first report of the rate at which fibromyalgia is being diagnosed in a community. This is also the first report of prevalence as assessed by the fibromyalgia research survey criteria. Our results suggest that patients, particularly men, who meet the fibromyalgia research survey criteria are unlikely to have been given a diagnosis of fibromyalgia.

INTRODUCTION

Fibromyalgia (FM) is a complex illness to diagnose and treat, with symptoms that may be part of or overlap with other diseases or syndromes. It is also a costly public health problem. Medical costs related to health care utilization and pain-related medications for patients with FM are substantially higher than those for patients without FM (1–4). Therefore, evaluating the prevalence of FM has both

clinical and economic relevance. Recognition of FM may not always be straightforward because FM symptoms may be part of or overlap with other diseases or syndromes.

Using the original 1990 American College of Rheumatology (ACR) criteria (5), Wolfe et al estimated that the prevalence of FM in the US general population is 2% (3.4% in women versus 0.5% in men) (6). Similarly, White et al (7), reporting on the London Fibromyalgia Epidemiology Study in Ontario, Canada, estimated the prevalence of FM at 3.3% (4.9% in women versus 1.6% in men), and Branco et al (8) reported on a multinational study of the prevalence of FM in 5 European countries, estimating it at 4.7%. A separate study using a method similar to that of

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Significance & Innovations

- This is the first prevalence study in the US using the 2010 fibromyalgia (FM) research criteria.
- Prevalence in the same population was calculated using 2 methods.
- Men who satisfy the 2010 FM research criteria are unlikely to be diagnosed with FM.

the ACR diagnostic criteria estimated the prevalence in Germany at 3.8%, with similar rates in men and women (9). These differing estimates may reflect differences in study populations, study designs, and measurements.

In 2010, the ACR published diagnostic criteria for FM that encompass the chronic widespread pain, fatigue, unrefreshing sleep, cognition, and somatic symptoms considered the hallmarks of this condition (10). These criteria were later modified to allow their use in epidemiologic and survey studies, without the requirement for an examiner to perform a tender point examination (11). The modification involved asking patients to report both pain and tenderness for the widespread pain index, in comparison to the ACR 2010 diagnostic criteria that only asked health care providers to determine areas of pain. Additionally, 3 representative items substituted for the comprehensive list of somatic symptoms that composed the ACR 2010 symptom severity score: 1) the presence or absence of headaches, 2) pain or cramps in the lower abdomen, and 3) depression in the past 6 months. Similar to the 2010 clinical criteria for FM, the modified criteria included a widespread pain index score of ≥ 7 and a symptom severity score of ≥ 5 . Alternatively, participants are defined as having FM if the widespread pain index is 3–6 or the symptom severity score is ≥ 9 . Additionally, symptoms must have been present at a similar level for at least 3 months. Routine use of these criteria in epidemiologic research may improve comparability of FM prevalence in different populations.

Our primary objective in this study was to estimate the prevalence of FM in a defined population in 2 different ways. To accomplish this objective, we first estimated the prevalence of diagnosed FM in clinical practice in Olmsted County, Minnesota, using community medical records. We then surveyed a random sample of the population of Olmsted County using the modified 2010 ACR criteria to estimate the percentage of responders who fulfilled the criteria.

PATIENTS AND METHODS

The study was approved by the Institutional Review Boards of both Mayo Clinic and Olmsted Medical Center. Patients were included in the study only if they were residents of Olmsted County who had granted permission for review of their medical records and had agreed to be contacted for research.

Rochester Epidemiology Project (REP). Most health care for residents of Olmsted County is delivered by 3 medical facilities and their affiliated hospitals: Mayo Clinic, Olmsted Medical Center, and the Rochester Family Medicine Clinic. Each institution uses a unit (or dossier) medical record system, whereby data from an individual (e.g., demographics, diagnoses, and billing records) are assembled in one place and are made available for approved research studies under the umbrella of the REP (12). The REP maintains an index of the diagnostic codes obtained from all of the participating providers. The REP diagnostic index includes diagnostic codes from the International Classification of Diseases, Ninth Revision (ICD-9) and from the Hospital Adaptation of the International Classification of Diseases (HICDA) for conditions identified by physicians during office visits or hospital stays. This index can be searched to identify groups of patients with a particular condition of interest in the Olmsted County population. The REP staff then facilitates access to the medical records at each institution, so that investigators can abstract details of medical care directly from the medical charts of patients. Virtually the entire Olmsted County population is captured by this system (13).

Subjects and case ascertainment. *Prevalence of diagnosed FM.* To identify patients with diagnosed FM (i.e., an FM diagnosis documented in the medical record), we used the REP diagnostic index and retrieved a list of all Olmsted County residents ages ≥ 21 years who had received a diagnosis using the HICDA code 07893-21-3 (FM) or the ICD-9 code 729.1 (myalgia, myositis, fibromyositis, or FM) between January 1, 2005, and December 31, 2009. Since these codes are not specific to FM and include diagnoses such as myalgias, myositis, and fibromyositis, we reviewed the individual medical records of all of the patients retrieved in this search to identify patients who had an FM diagnosis documented by a health care provider in a clinical note in the medical record.

Prevalence of FM in the general population of Olmsted County. We estimated the prevalence of FM in the Olmsted County population by mailing a survey that included the modification of the 2010 ACR criteria for FM (11). For the purposes of this study, we refer to this survey as the “FM research survey.”

Because the REP captures data on virtually the entire Olmsted County, Minnesota, population, it serves as an ideal, population-based sampling frame for survey studies (13). We used the REP research infrastructure to identify all residents of Olmsted County in 2010. We then used the REP to identify a stratified random sample of 2,994 adults in Olmsted County and mailed the FM research survey to them. We sampled approximately equal proportions of men and women across the 3 age strata (21–39 years, 40–59 years, and ≥ 60 years). To maximize the response rate, we sent a reminder postcard at 2 weeks (only to nonrespondents), and at 4 weeks we sent a second survey (only to nonrespondents). For survey respondents who met FM survey criteria, we reviewed their medical

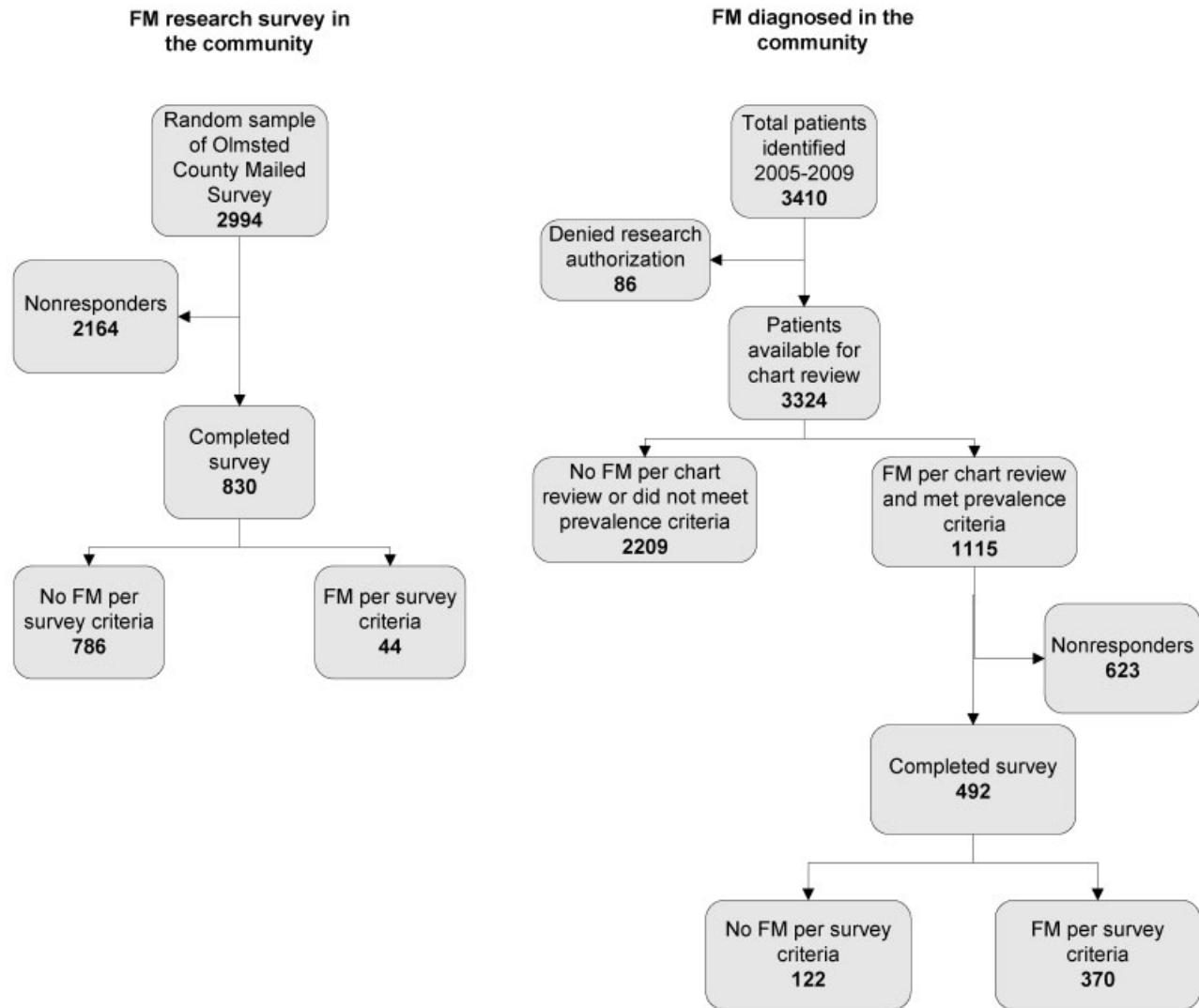


Figure 1. Flow chart of participant identification by methodology. FM = fibromyalgia.

records to determine whether they had also received a diagnosis of FM from a health care provider.

FM research survey in patients with a diagnosis of FM. Patients with physician-diagnosed FM who were identified through the medical record review were also mailed the FM research survey. This step was taken to determine the percentage of these patients who also met the FM research survey criteria. To maximize the response rate, we sent a reminder survey to this group at 4 weeks (only to nonrespondents).

Statistical analysis. To estimate the prevalence of diagnosed FM, we identified all adults (ages ≥ 21 years) who were alive and residing in Olmsted County on December 31, 2009, who had a diagnosis of FM in their medical record. An overall crude rate of prevalence was estimated on the basis of the proportion of all prevalent cases among the entire adult population in the county (as enumerated using census figures), and likewise for age- and sex-specific prevalence computed within those strata. Age- and sex-adjusted prevalence was then computed us-

ing direct standardization to the total US population for the year 2000 (14). Ninety-five percent confidence intervals (95% CIs) were estimated, assuming that the prevalent cases followed a binomial distribution.

In our second approach, we surveyed a random sample of the county for FM symptoms using the FM research survey. We then estimated the prevalence of survey-based FM to be the proportion of all respondents who met FM survey criteria. Because of the method of sampling (age- and sex-stratified random sampling), the sample from which this prevalence estimate was derived differs from the population of Olmsted County adults that served as the denominator in the first approach. However, when the same direct adjustment approach (as described above) was applied, the resulting age- and sex-adjusted prevalence of survey-based FM could be more directly compared to the prevalence of clinically-diagnosed FM.

In addition, descriptive statistics were used to summarize demographic, comorbid, and clinical characteristics of the diagnosed and survey-based prevalence cases. For a formal comparison of characteristics between these 2

Table 1. Prevalence by age and sex of diagnosed and reported FM in residents of Olmsted County, Minnesota*

Type of rate	Diagnosed FM in Olmsted County†			Survey-based FM from random sample‡			
	Count	Prevalence, %	95% CI	Count	Denominator	Prevalence, %	95% CI
Age 21–39 years							
Unadjusted (women)	151	0.74	0.62–0.86	9	84	10.71	4.90–20.34
Unadjusted (men)	17	0.09	0.05–0.14	3	58	5.17	1.07–15.12
Unadjusted (total)	168	0.42	0.35–0.48	12	142§	8.45	4.37–14.76
Age 40–59 years							
Unadjusted (women)	519	2.62	2.40–2.85	8	143	5.59	2.42–11.02
Unadjusted (men)	28	0.15	0.10–0.22	8	123	6.50	2.81–12.82
Unadjusted (total)	547	1.42	1.30–1.54	16	266¶	6.02	3.44–9.77
Age 60–110 years							
Unadjusted (women)	376	3.14	2.83–3.48	12	199	6.03	3.12–10.53
Unadjusted (men)	24	0.27	0.17–0.40	4	223	1.79	0.49–4.59
Unadjusted (total)	400	1.91	1.73–2.11	16	422#	3.79	2.17–6.16
All ages							
Unadjusted (women)	1,046	2.00	1.88–2.12	29	426	6.81	4.56–9.78
Unadjusted (men)	69	0.14	0.11–0.18	15	404	3.71	2.08–6.12
Unadjusted (total)	1,115	1.12	1.05–1.18	44	830**	5.30	3.85–7.12
Age adjusted (women)	1,046	2.00	1.88–2.12	29	426	7.71	4.65–10.77
Age adjusted (men)	69	0.15	0.12–0.19	15	404	4.88	2.08–7.69
Age and sex adjusted (total)	1,115	1.13	1.07–1.20	44	830	6.36	4.28–8.44

* FM = fibromyalgia; 95% CI = 95% confidence interval.
 † Data from the Rochester Epidemiology Project for patients with a clinical diagnosis of FM in the medical record.
 ‡ Data from responses to the survey conducted in 2011.
 § Response rate of 16.2% among 877 subjects ages 21–39 years.
 ¶ Response rate of 25.7% among 1,036 subjects ages 40–59 years.
 # Response rate of 39% among 1,081 subjects ages ≥60 years.
 ** Response rate of 27.7% among 2,994 subjects (full sample).

groups, the 2-sample *t*-test or the chi-square test was used, as appropriate. Poisson regression analysis was used to formally test for age and sex trends in prevalence. *P* values less than 0.05 were considered statistically significant.

RESULTS

Prevalence of diagnosed FM. Using the REP medical index, we identified 3,410 patients with the HICDA code 07893-21-3 or the ICD-9 code 729.1 for the period between January 1, 2005, and December 31, 2009. Of these 3,410 patients, 86 (2.5%) denied consent for medical record review and 160 (4.7%) were not residents of Olmsted County in 2009 (Figure 1). We reviewed the medical records of the remaining 3,164 patients, and identified 1,115 patients with an FM diagnosis documented in the medical record by a health care provider. The age- and sex-adjusted prevalence of diagnosed FM in Olmsted County was estimated at 1.1% (95% CI 1.07–1.20%) (Table 1). Prevalence estimates increased with age (0.42% for the age group 21–39 years, 1.42% for the age group 40–59 years, and 1.91% for the age group ≥60 years; *P* < 0.001). The age-adjusted prevalence rate in women was significantly higher than that in men (2.00% versus 0.15%; *P* < 0.001 for each). The 95% CIs for these estimates are shown in Table 1.

Prevalence of FM in the general population of Olmsted County. Overall, 830 (27.6%) of the stratified random sample of 2,994 Olmsted County residents responded to the survey (Table 1). Of the 830 respondents, 44 (5.3%) met the FM research survey criteria (Figure 1). On the basis of this sample and method, the age- and sex-adjusted prevalence of FM in the general population of Olmsted County was estimated to be 6.4% (Table 1). Although not statistically significant, the prevalence of FM tended to be higher in women than in men (7.71% versus 4.88%; *P* = 0.08, adjusted for age). There was also a borderline association of higher prevalence in younger ages (8.45% in the age group 21–39 years, 6.02% in the age group 40–59 years, and 3.79% in the age group ≥60 years; *P* = 0.05, adjusted for sex), which is in contrast to the trend of increasing prevalence of diagnosed FM with older age. The 95% CIs for these estimates are shown in Table 1.

Comparison of responders who met the FM research survey criteria in either group. Overall, 492 (44%) of the 1,115 patients with diagnosed FM responded to the mailed FM research survey. Of these, 370 (75%) met the FM research survey criteria (Table 2). Compared to the responders to the survey from the general population of Olmsted County who met the FM research survey criteria, the group with diagnosed FM who also met the FM research survey criteria included significantly fewer men (6% versus 34%; *P* < 0.001), and on average had higher symptom severity scores (mean ± SD score 11.8 ± 3.8

Table 2. Comparison of clinically diagnosed and Olmsted County population who met FM research survey criteria*

	Diagnosed FM cases who met survey criteria (n = 370)†	Olmsted County population who met FM survey criteria (n = 44)	P
Age, mean ± SD years	55.7 ± 12.7	54.9 ± 17.6	0.69
Sex, no. (%)			< 0.001
Male	21 (6)	15 (34)	
Female	349 (94)	29 (66)	
Responders with survey-based FM			
FM score, mean ± SD	20.2 ± 4.8	16.7 ± 4.1	< 0.001
Symptom severity score, mean ± SD	11.8 ± 3.8	8.6 ± 3.6	< 0.001
Widespread pain score, mean ± SD	8.4 ± 2.0	8.0 ± 2.0	0.23
Fatigue‡	336/370 (91)	40/44 (91)	0.98
Trouble thinking‡	231/370 (62)	24/44 (55)	0.31
Waking up tired‡	324/369 (88)	37/44 (84)	0.48
Pain/cramps	251/367 (68)	27/41 (66)	0.74
Depression	254/366 (69)	26/43 (60)	0.23
Headache	312/365 (85)	33/42 (79)	0.24

* Values are the number/total (percentage) unless otherwise indicated. FM = fibromyalgia.
† 370 diagnosed FM cases (75%) who met the FM survey criteria based on the subset of 792 responders.
‡ Moderate to severe.

versus 8.6 ± 3.6 ; $P < 0.001$) (Table 2). Additionally, only 12 (27.2%) of the 44 responders to the survey from the general population of Olmsted County who met the FM research survey criteria had an FM diagnosis from a health care provider.

DISCUSSION

The age- and sex-adjusted prevalence of diagnosed FM in Olmsted County (the rate at which FM is being diagnosed in the community of Olmsted County) was 1.1%. Since this study is the first to examine the prevalence of diagnosed FM in the county, it is not possible to directly compare this estimate with other prevalence estimates. The age- and sex-adjusted prevalence of FM as assessed by the FM research survey was 6.4%. Since, to the best of our knowledge, this is the first study to estimate the prevalence of FM as assessed by the FM research survey, it is not possible to directly compare this estimate with other prevalence estimates. These are 2 distinct prevalence rates utilizing 2 different methodologies (i.e., the rate at which FM is being diagnosed in the community and the percentage of people in the community who self-report symptoms that constitute criteria for the FM research survey). These prevalence rates can only be interpreted within the context of the methodology utilized.

Although the rate of diagnosis of FM in the community is 1.1%, the actual prevalence of the syndrome in the community may be higher. Possible reasons for underestimation could include the lack of systematic assessment of FM in the clinic, lack of consideration of the diagnosis of FM, physician beliefs regarding the diagnosis of FM, or if the focus of the medical visit was another medical problem. The estimate, however, is very important, since this is the first study to assess the actual diagnosed prev-

alence. One could importantly conclude that FM is not being diagnosed as often as might have been the case had there been systematic assessment.

Similarly, although the FM research survey criteria are modified from the FM clinical criteria, they are not equivalent. The assessment of eligibility of 2010 FM clinical criteria occurs in a clinical setting during a detailed, face-to-face assessment. In contrast to this, the FM research survey is designed to be an instrument to self-report (not self-diagnose) symptoms of FM and is validated for epidemiologic studies to estimate the number of people who endorse the symptom constellation of FM. Therefore, the FM research survey criteria can only be interpreted as meeting "survey criteria" and not meeting "clinical criteria."

Additionally, the prevalence of FM, as assessed by the FM research survey criteria, unexpectedly showed a negative association with age. This is unexpected, since increasing prevalence of FM with age is a consistent finding in previous reports (7,15). The most likely explanation for this is participation bias and, given that the lower response rates we observed corresponded to the younger ages, it seems plausible that subjects with higher disease activity were overrepresented among younger participants.

Compared to men, the age-adjusted prevalence rates of FM in women were significantly higher for both the survey-based estimates and the clinical diagnosis estimates. In women, the prevalence of survey-based FM was nearly 3-fold higher than the prevalence of clinically diagnosed FM. In men, the difference was even greater, with the prevalence of survey-based FM 20-fold higher than the prevalence of clinically diagnosed FM. These data highlight a key difference between the 1990 criteria (which require the presence of 11 or more tender points) and the 2010 criteria. Women innately have many more tender

points than men (16), and therefore it is possible that even if a woman and a man have the same exact symptom profile suggesting FM, the man is much less likely to meet the 1990 criteria because he is much less likely than the comparable woman to also have 11 tender points. Another explanation for the sex differences in our study is that men in Olmsted County tend to visit medical providers less frequently than women do (12). Alternatively, health care providers may be less likely to diagnose FM in men than in women.

We also noted that the survey responders meeting the FM research survey criteria in the general population had symptom severity scores that were statistically less severe than those of survey responders meeting the FM research survey criteria who had also been diagnosed with FM. One likely explanation for this finding could be that the illness was not as distressing to this group or that they did not seek care for reasons that remain unknown. Another likely explanation of why the diagnosis of FM was not made by health care providers in persons with lower scores may be that they presented differently. However, a review of medical records of the 44 subjects who met the criteria demonstrated that 50% of them had at least one rheumatologic disorder. Therefore, the explanation for our findings requires further study.

A strength of our study is that we assessed the prevalence of FM in a defined population using 2 different methods. Our use of the REP data allowed us to identify all FM diagnoses in the Olmsted County population within a defined period. The same population then served as a sampling frame to assess the prevalence of FM using the FM research survey. These 2 methods allowed us to determine whether FM might be diagnosed less often than it is actually prevalent in the Olmsted County population. The differing methodologies also contribute to the differences observed. Wolfe et al reported that the modified ACR 2010 criteria were satisfied by only 60% of the patients with a prior diagnosis of FM (11).

Limitations of our study include the low participation rate in the survey of the Olmsted County population overall (27.7%), with a very low rate (16.2%) in the 21–39-year age category. Because of this low participation rate and the unexpectedly high FM rate in this category, our estimates of FM in the general population are likely biased. If persons with FM were more likely to complete the survey, then our prevalence estimates of FM would be inflated. Based on the assumption that having FM is associated with increased comorbidity, we tested but found no significant difference in Charlson Index scores between survey responders and nonresponders in the youngest age group. However, in the overall sample, we found a significant interaction between age and the Charlson Index that indicated healthy older subjects were more likely to respond and therefore overrepresented in the subgroup of participants. Sex could also have accounted for bias in the prevalence estimates, given its association with both survey FM and participation.

Another limitation of our study is that we were reviewing medical records already in existence. Since this was a medical record review, we were limited to the information that was previously recorded at the time of a clinical

encounter. A physician reviewed all of the medical records for the presence of chronic widespread pain and tender points. However, the exact number of tender points was not always specified.

The age- and sex-adjusted prevalence of diagnosed FM in Olmsted County was 1.1%, whereas the prevalence of FM in Olmsted County by the survey method was 6.4%, which is higher than most previous estimates. Our study results suggest that persons (especially men) who satisfy FM research criteria are unlikely to be diagnosed with FM.

AUTHOR CONTRIBUTIONS

All authors were involved in drafting the article or revising it critically for important intellectual content, and all authors approved the final version to be published. Dr. Vincent had full access to all of the data in the study and takes responsibility for the integrity of the data and the accuracy of the data analysis.

Study conception and design. Vincent, Clauw, Oh, Barton, St. Sauver.

Acquisition of data. Vincent, Lahr, Clauw, Whipple.

Analysis and interpretation of data. Vincent, Lahr, Wolfe, Clauw, Whipple, Barton, St. Sauver.

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