

Fibromyalgia Syndrome in an Amish Community: A Controlled Study to Determine Disease and Symptom Prevalence

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ABSTRACT. Objectives. To estimate the point prevalence of fibromyalgia syndrome (FM) in Amish adults and to compare the prevalence of chronic pain, chronic widespread pain, FM, chronic fatigue, and debilitating fatigue in the Amish versus non-Amish rural and urban controls. The *a priori* assumption was that, if litigation and/or compensation availability have major effects on FM prevalence, then FM prevalence in the Amish should approach zero.

Methods. We surveyed 242 Amish adults in a small rural community southeast of London, Ontario, Canada. Individuals were screened using a validated screening instrument. Those reporting chronic, widespread pain were examined for FM using published classification criteria. Amish results were compared to results collected in a random telephone survey of 492 non-Amish adults living in rural Southwestern Ontario and 3395 non-Amish adults previously surveyed in London.

Results. Pain lasting at least one week in the preceding 3 months was reported by 34.3% of the Amish; pain in the upper extremities by 25.4%, in the lower extremities by 22.5%, and in the trunk by 28.1%. Twenty-six (15 women, 11 men) reported chronic, widespread pain. Eleven FM cases were confirmed among women (age adjusted point prevalence, $p = 10.4\%$) and 2 among men ($p = 3.7\%$) for an overall age and sex adjusted prevalence of 7.3% (95% CI 5.3, 9.7); this was both statistically greater than zero ($p < 0.0001$) and greater than in either control population (both $p < 0.05$).

Conclusion. FM is relatively common among the Amish. (J Rheumatol 2003;30:1835–40)

Key Indexing Terms:

FIBROMYALGIA

EPIDEMIOLOGY

PREVALENCE

AMISH

Fibromyalgia syndrome (FM) is a chronic, disabling condition¹⁻³ that appears to have a worldwide distribution⁴⁻¹⁰. US data suggest that it accounts for a significant percentage of patients seen in family practice clinics (2.1%)¹¹, general medicine clinics (5.7%)¹², and hospitals (7.5%)¹³. In Canada, it is one of the 3 most common chronic rheumatic disorders among new patients presenting to rheumatology clinics, where its prevalence may be increasing¹⁴. An estimated 700,000 Canadian adults have FM¹⁵, resulting in \$350 million in direct health care costs¹⁶ and \$200 million in private insurance costs¹⁷ annually. In the noninstitutionalized, general adult population of London, Ontario, it affects 5.7% of women and 1.7% of men¹⁸.

Current knowledge of risk factors for FM is limited¹⁹. Our own data from the London Fibromyalgia Epidemiology Study (LFES) show that female sex, middle age, less education, and lower household income all are risk factors for

having FM. The same risk factors were identified in Wichita, Kansas²⁰. Certain types of trauma appear to be associated with as much as a 13-fold increased risk, even in the absence of litigation or work disability²¹. However, there are some who consider FM to be factitiously driven by misinformed media reports²² and an overly liberal disability compensation system²³.

There are several reasons to study FM in the Amish. First, Amish communities culturally are very distinct and purposefully isolated from the rest of North American society²⁴. The Amish do not use any form of electricity, and hence do not possess radios, televisions, tape recorders, compact disc or record players, computers, and faxes. They do not own telephones, although most communities will utilize a public telephone, on occasion, but usually only to conduct essential business²⁴. They do not subscribe to newspapers, magazines, or journals outside the global Amish community²⁴. They do not own any motorized vehicles, including automobiles²⁴. They also rarely enter non-Amish public establishments, with the exception of hospitals, doctors' offices and other health care facilities, the post office, and smaller stores to buy supplies²⁴. This combination of factors drastically limits their exposure to non-Amish media influences and, hence, any potential effect of these reports on Amish community behavior.

Second, in accord with Amish practice, community

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members do not utilize municipal, provincial/state, or federal disability compensation systems²⁴. Generally, the only recourse for a disabled community member is to request financial or other assistance from the bishop of the local congregation, who then appeals for donations from congregation members. Congregations are small, their size limited because all services take place within the homes of congregation members. Hence, funds are limited, and not dispensed anonymously. There also is a very strong work ethic and sense of independence among the Amish. For these and other reasons, it is uncommon for community members to seek financial assistance related to physical disability. If FM is a media, litigation, or compensation-driven ailment, it should be uncommon, if present at all, in the Amish.

Our primary objective was to estimate the point prevalence of FM in Amish adults living in a small rural community. The null hypothesis was that the point prevalence of FM is zero. Secondary objectives were to compare the prevalence of chronic pain, chronic widespread pain (CWP), fibromyalgia, chronic fatigue, and debilitating fatigue in the Amish versus non-Amish rural controls and non-Amish urban controls. All null hypotheses are that the point prevalences will be equal in the 3 population groups. Our *a priori* assumption was that, if litigation has a major effect on the prevalence of FM and FM related symptoms, then the prevalence of FM and FM related symptoms should be less in Amish versus non-Amish populations.

MATERIALS AND METHODS

Recruitment of subjects. The study involved 3 study populations. Since the size of the Amish community was fixed, the required sample size for non-Amish rural and non-Amish urban controls was calculated as 500 per group, to permit an estimate of CWP prevalence $\pm 0.5\%$, assuming 75% participation.

Population 1: Amish adults. The target population was Amish residents of rural Southwestern Ontario. Using a registry of North American Amish communities²⁵ we identified several Amish communities within 100 kilometers of London. Registered data on these communities included the number of congregations and families per community. Aylmer was selected for study because of its proximity to London (20 km) and the size of the community (80 registered adult couples with an estimated 250 Amish adults). Moreover, the Aylmer Amish Directory²⁶ provided us with the names of all members of the Aylmer Amish community including birth dates, addresses, and 4-generation genealogy data.

Using the Aylmer Amish Directory, a list of all individuals age 18 years or greater was drafted as the sampling frame. Since the Amish generally do not possess telephones, a telephone survey was impossible. Hence, after obtaining approval of the 3 community bishops, potentially eligible subjects were recruited at the time of 2 successive bimonthly joint school meetings (these meetings generally are attended by the male head of each household, even households in which there are no school-age children, and attendance approaches 100%). A study packet was distributed to each family's male representative, with the name of that family marked on the external envelope. Each packet included an introductory letter, a consent form, and a 2 page screening questionnaire for each adult in that household, in addition to 2 stamped, self-addressed envelopes in which completed questionnaires could be returned. In addition, one Amish community member in high community standing had agreed to ensure that every family received and returned a study packet.

Population 2: Non-Amish rural controls. An internal group of rural controls consisted of 500 noninstitutionalized consenting adults recruited by random selection from the areas in and around Aylmer, Ontario. Subjects were recruited in a telephone survey using a computer generated list of random telephone numbers within the 2 Aylmer area exchanges. As in the LFES, a random telephone survey of 3395 noninstitutionalized consenting adults living in London, Ontario⁵, the sampling unit was a residence with at least one telephone number. One eligible adult per household was randomly selected for interview, in accord with the LFES protocol. (As with LFES, we chose not to select more than one adult per household to avoid clustering and to allow us to accurately estimate the denominator of our sample.)

Population 3: Non-Amish urban controls. An external group of 3395 urban controls already had been identified and studied in LFES. Prevalence of FM and CWP already had been estimated both for men and women in this population. In addition, 100 confirmed cases of FM were identified, for whom clinical and functional data already had been collected.

Screening for and confirming FM. The screening instrument we used was the LFES Screening Questionnaire (LFESSQ), a 4-item screening questionnaire that has been pretested and found to have a sensitivity of 100%, specificity of 53%, test-retest reliability of 100% among those who screen negative, and a positive predictive value of 57%²⁷. Additional questions were asked regarding age, sex, and work status. As described above, the questionnaire was delivered to eligible Amish residents in written form and to rural and urban controls by telephone interview. Test-retest reliability already had been examined for the LFESSQ delivered by written versus verbal questionnaire, and found to be 90–100%.

All subjects who screened positive for chronic, widespread musculoskeletal pain on the LFESSQ were invited for a brief physical examination by a rheumatologist (KPW) either at the subject's home or at a satellite clinic in Aylmer. The primary objective of this evaluation was to confirm or exclude FM, using the 1990 American College of Rheumatology (ACR) classification criteria for FM²⁸.

Data analysis. For each group, point prevalence was calculated as the number of confirmed cases of FM divided by the number of eligible adults in the sample population. A second estimate adjusted for nonparticipation among positive screens, assuming the same prevalence of FM among positive screens who refused to be examined as among those who agreed. Each of the above estimates was adjusted both for age and sex by direct age standardization, using 1991 census data for Aylmer County. Ninety-five percent confidence intervals were constructed using logit transformation to correct for proportions approaching zero²⁹. Hypothesis testing was performed using Pearson chi-square analysis with significance at $p < 0.05$.

RESULTS

Demographics of the 3 samples. We successfully completed surveys on 179 Amish, 492 rural non-Amish, and 3395 urban non-Amish adults (Table 1). Percentage of women was approximately 60% for each of the samples. The Amish cohort tended to be younger ($p < 0.001$), likely reflecting the greater number of children born to Amish couples. No Amish reported being divorced (divorce is not accepted by the Amish community). Only 0.6% reported being widowed, compared to 13.0% of rural and 8.1% of urban controls ($p < 0.05$). Less than 2% of the Amish considered themselves to be either retired or disabled, compared to 28.7% of non-Amish rural controls and 20.2% of urban controls ($p < 0.001$).

Prevalence of pain, fatigue, and FM in Amish adults. We distributed questionnaires to all 242 Amish adults listed in the Aylmer Amish Directory. Within 4 weeks, 179 were

Table 1. Demographics of the 3 population samples. Except where stated, all results are expressed as percentages.

	Amish	Non-Amish Rural	London Urban
Sample size, n	179	492	3395
Female, %	56.7	60.4	61.8
Mean age, yrs	34.7	49.0	42.6
Age, %			
18–24	26.4	10.6	15.3
25–34	36.5	12.2	22.6
35–44	12.4	19.5	22.5
45–54	10.7	20.3	13.6
55–64	11.8	13.8	9.0
65–74	1.1	11.0	9.2
75+	1.1	11.8	5.8
Never married	33.7	14.4	29.5
Married	65.7	58.7	49.5
Divorced or separated	0.0	13.8	12.3
Widowed	0.6	13.0	8.1
Working (including fulltime housework)	98.3	71.3	79.8

returned (74.0%). One hundred two respondents were women (57.0%); this compared to a sex distribution of 52.3% in the Aylmer Amish Directory. Mean age was 34.7 years with a range 18 to 93 years.

Pain lasting at least one week in the preceding 3 months was reported by 34.3% of the Amish. Pain was reported in the upper extremities by 25.4%, in the lower extremities by 22.5%, and in the trunk by 28.1% (Table 2). Twenty-six subjects (15 women, 11 men) reported chronic, widespread pain and hence were considered positive screens for FM. All 26 agreed to be examined.

Thirteen percent reported previously having been diagnosed with arthritis and 2.8% with FM. Four women and one man had been previously diagnosed with FM. Eleven cases of FM were confirmed among women (age adjusted point prevalence, $p = 10.4\%$) and 2 among men ($p = 3.7\%$), for an overall age and sex adjusted prevalence of 7.2% (95% CI 5.3, 9.7). Since participation among positive screens was

100%, there was no need to reestimate prevalence adjusting for nonparticipation.

Frequent fatigue was reported by 40.4% of the Amish sample, and debilitating fatigue by 21.3%.

Prevalence of pain, fatigue, and FM in non-Amish rural controls. The total sample included 492 noninstitutionalized adults. The sample consisted of 297 women (60.4%) and 194 men (one subject refused to identify their sex); this compared to sex distribution data for Aylmer and surrounding area estimated at 52% female³⁰. Mean age was 49.0 years with a range of 18 to 96 years.

Almost half (48.4%) reported some pain lasting more than one week in the preceding 3 months: 25.4% reported upper extremity pain, 24.2% lower extremity pain, and 37.4% trunk pain; 28.9% reported having been diagnosed with arthritis, only 1.0% with fibromyalgia/fibrositis; 8.9% reported chronic, widespread pain consistent with the first ACR criteria for FM.

Table 2. Prevalence of pain, chronic widespread pain, fibromyalgia, frequent fatigue, and debilitating fatigue in the 3 groups (expressed as percentages).

Prevalence	Amish	Non-Amish Rural	London Urban
Chronic pain	34.3	48.4	34.8
Chronic, widespread pain	14.5	8.9	7.3
Upper extremity pain	25.4	25.4	21.3
Lower extremity pain	22.5	24.2	17.9
Neck, back, and/or chest pain	28.1	37.4	16.7
Previously diagnosed with			
Arthritis	12.9	28.9	22.6
Fibromyalgia	2.8	1.0	7.2
Estimated prevalence of fibromyalgia	7.3	1.2	3.8
Frequent fatigue	40.4	66.7	54.5
Debilitating fatigue	21.3	23.8	21.5

Unfortunately, likely because of the distance to travel from Aylmer to the London Health Sciences Centre for the confirmatory examination, only 14 of 33 positive screens agreed to be examined by a rheumatologist to confirm or exclude FM. Age adjusted prevalence was estimated as 2.2% among women (95% CI 0.5, 3.9). No case of FM was confirmed among men.

Two-thirds (66.7%) reported frequent fatigue and 23.8% fatigue that, in itself, significantly limited their activities. Frequent fatigue was more common among women (71.4% vs 59.8%; chi-square = 0.04) as was debilitating fatigue (31.0% vs 12.9%; chi-square < 0.001).

Prevalence of pain, fatigue, and FM in non-Amish urban controls. Details of participation in the LFES urban sample are published elsewhere¹⁸. Of 4674 potentially eligible subjects, 3395 (72.6%) completed the screening interview; 61.6% of respondents were women compared to 52.7% women in the adult London population³¹. We examined 176 (71.0%) of the 248 subjects who screened positive.

Recalling the previous 3 months, 34.8% of the survey sample reported having had some musculoskeletal pain lasting at least one week: 36.1% of women, and 32.6% of men [odds ratio (OR) = 1.16, 95% CI 1.00, 1.35]. A much smaller percentage, 7.3% (n = 248), reported having had chronic widespread pain. Widespread pain also was more commonly reported by women (9.0% vs 4.7%, OR 2.02, 95% CI 1.49, 2.77).

More than half of the survey sample, 54.5%, reported having had frequent fatigue over the previous 3 months and, for 21.5%, this fatigue was debilitating enough to significantly limit their activities. As with chronic pain, women were more likely to report fatigue than men, 60.0% versus 45.0% reporting frequent fatigue (OR 1.84, 95% CI 1.60, 2.13), 25.1% versus 15.3% reporting activity-limiting fatigue (OR 1.86, 95% CI 1.55, 2.25).

Women were more likely to report having been previously told they had arthritis (26.3% vs 16.6%; OR 1.80, 95% CI 1.50, 2.15) and fibromyalgia (8.6% vs 4.9%; OR 1.83, 95% CI 1.35, 2.51).

One hundred FM cases were confirmed among the 176 who were examined. The unadjusted and nonparticipation adjusted estimates of FM prevalence, adjusted both for age and sex, were 2.7% (2.6, 2.8) and 3.8% (3.7, 3.9) respectively. For women and men, adjusted prevalences were estimated as 5.7% and 1.7%, respectively.

Hypothesis testing. The point prevalence of FM in the Amish was found to be statistically significant from zero (greater than zero) at a level of $p < 0.0001$. Interestingly, we also found that the point prevalence of FM was greater than that in either of the 2 non-Amish control populations, rural and urban controls (both $p < 0.05$).

DISCUSSION

This was a pilot study to assess the point prevalence of FM

in a small Amish community in Southwestern Ontario. The *a priori* assumption of the study was that if litigation has a major effect on the prevalence of FM and FM related symptoms, as some have suggested, then the prevalence of FM and FM related symptoms should be less in Amish versus non-Amish populations; indeed, it should approach zero. However, in this study of 178 Amish adults in a single, small Amish community southeast of London, we found that FM prevalence was clearly greater than zero. Somewhat surprisingly, FM prevalence was higher in this population than in any other previously reported population, except one⁵. It was also statistically greater than what we observed in urban London and a rural community southeast of London.

Our results suggest that litigation does not have a significant augmenting effect on FM prevalence. A review of previous FM prevalence studies worldwide lends further support to the relative unimportance of litigation and compensation on FM prevalence. These studies have shown FM to be more common in countries in which compensation availability might be expected to be less (for example, Pakistan³², Poland⁸, and South Africa⁷) than in countries in which compensation availability might be expected to be greater (Sweden³³, Denmark³⁴, and Finland⁴).

Although there may be no significant effect of litigation and compensation on FM prevalence, it is reasonable to ask if these factors might affect the expression of FM, in terms of symptom severity and level of disability. Is it possible that individuals in this culturally isolated society express their FM differently? That, unfortunately, is not a question our study can adequately address, due to inadequate numbers of confirmed Amish FM cases. It is, however, a reason to further study the prevalence and expression of FM in the Amish. Currently, this research group is studying 2 larger Amish communities north of London. Data from these 3 Amish communities will be compiled and compared with respect to symptom severity and disability, versus further rural controls and our pre-analyzed London population.

Yet another reason to study FM in the Amish further is that the Amish have impeccable genealogy records and very high rates of inbreeding that drastically limit the gene pool³⁵. This is an ideal population in which to study genetic influences on disease prevalence. In one Ohio Amish community, every one of 19 cases of cystic fibrosis among 10,816 live births was traced to a single ancestral couple born in the 1700s³⁶. In another study, all 8 cases of congenital hemolytic anemia and red cell pyruvate kinase (PK) deficiency in Geauga County, Ohio, were traced to a single ancestor who had lived in Mifflin County, Pennsylvania³⁷. Other epidemiologic research in Amish populations has led to evidence of familial clustering of type 2 diabetes mellitus³⁸, chromosomal abnormalities in congenital glaucoma³⁹, limb-girdle muscular dystrophy⁴⁰, manic depression⁴¹, and hemophilia B⁴². Other disorders that appear to cluster in the Amish include rubella⁴³, cartilage-hair

hypoplasia⁴⁴, and glutaric aciduria type I⁴⁶. If FM is indeed more prevalent in the Amish than non-Amish, as our pilot data suggest, the Amish population is ideal for assessing potential genetic or familial effects. In future studies, we propose to examine whether familial clustering occurs and why. If results warrant, this could lead to further genetic studies in this population.

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