

# Community based study to estimate prevalence, burden of illness and help seeking behavior in rheumatic diseases in Mexico City. A COPCORD study

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## Abstract

### Objective

To estimate the prevalence, burden of illness and help seeking behavior of musculoskeletal complaints and provide point prevalence estimates of osteoarthritis, low back pain, fibromyalgia, rheumatoid arthritis and gout among adult population in a suburban community in Mexico city.

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### Methods

Home survey of adults in a balanced and stratified sample validated against physical exam. Three trained interviewers applied a validated COPCORD core questionnaire. Subjects with pain (in the last seven days or ever)  $\geq 4$  (0-10) and no trauma; or with current or past disability were evaluated preferably the same day by a trained clinician in a structured interview. A diagnosis using ACR criteria when available, recommendation or referral was provided as required. Analysis was based on descriptive statistics of participant characteristics, pain site and distribution, patterns of help seeking behavior. Point prevalence with 95% confidence intervals of most common diseases and associated disability rate.

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### Results

1169 men and 1331 women were included. Pain in the last 7 days not associated with trauma was reported in 419 (17%) participants. The most common sites of involvement were knee (12.3%); low back (6.3%); ankles (6%) and shoulders (5.3%). The mean/SD pain score was 4.8/2.5. Thirteen percent of the total sample had some treatment. The general practitioner treated 72% of those; 75% perceived good efficacy with medications. Point prevalence estimates and 95% CI were: disability: 1.4% (0.0 – 1.9); osteoarthritis: 2.3% (1.7 – 2.9); fibromyalgia: 1.4 (1.0 – 2.0); low back pain: 6.3% (5.4 – 7.3); rheumatoid arthritis: 0.3% (0.1 – 0.6) and gout 0.4% (0.1 – 0.7).

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### Conclusion

Pain in the last 7 days due to musculoskeletal disorders is 17% in this community. Medications were commonly prescribed. Point prevalence estimates of most common diagnoses was similar to other community surveys using COPCORD methodology but very different help seeking behavior.

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### Key words

Epidemiology, rheumatic diseases, help seeking behavior, rheumatoid arthritis.

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## Introduction

Rheumatic diseases are an heterogeneous group of illnesses with more than two hundred specific diagnoses. They have a wide range of severity, varying from self-limited to life-threatening conditions. In general, they are not usually considered as priority health problems in most health systems; nevertheless they have a high prevalence (1), their treatment is expensive (2) and pain and disability are common complaints interfering with quality of life (3). It has been shown that medical treatment of these patients is not always easy, family doctors have a diagnostic accuracy of musculoskeletal problems of only 49% and they tend to use expensive diagnostic techniques (4). The use of non-conventional therapies by subjects with musculoskeletal complaints is very common (5-8); the same is true for self medication (9) and both practices run a high risk of the patient not receiving appropriate treatment and follow-up for specific diagnoses (7).

The epidemiology of rheumatic diseases and help seeking behavior in Mexico is unknown. Available information is provided by referral centers that do not represent what is taking place at a community level. The Community Oriented Program for the Control of Rheumatic Diseases (COPCORD studies) has been designed through an initiative of the International League of Associations of Rheumatology (ILAR) to estimate the burden of illness due to musculoskeletal disorders and implement diagnostic strategies at a community level. COPCORD studies have been done in several developing countries around the world (10-20). In general, these studies have shown that musculoskeletal complaints are highly prevalent in the community, that diagnostic accuracy is low and that most patients are not receiving an appropriate treatment.

We carried out this study to estimate the prevalence of musculoskeletal complaints at a community level, to provide point prevalence estimates of the most common rheumatic diseases and to identify the patterns of help seeking behavior in a suburban community in

Mexico City. This study was approved by the Institutional review board and funded by CONACYT, a Mexican agency supporting science and technology.

## Material and methods

### Study design

Cross sectional home survey applied by trained interviewers to 2500 subjects older than 18 years old. Results were validated against physical examination in selected cases.

### The community

This survey was carried out in San Pedro Martir, a suburban community located in the Southwest region of Mexico City. By the time the study was done, an estimated population of 30,000 was registered. It is located 5 km South of our institution. It has an updated census in which 49% were older than 18 years. 70% of working adults are employed. 87% of parents have finished at least 6 years of formal education, a mandatory level of education in Mexico. For more than 15 years, our institution has been involved in several epidemiology projects in this community especially in the area of diarrhea (21, 22), breastfeeding (23) and pharmacoepidemiology (24). The community identifies people from our institution as compromised with them and the participation rate was 99% in our pilot COPCORD study (14). There are around 20 general practitioners in the community and approximately 20 private pharmacies. A health center is located in the community, where primary care is offered by the official health sector. There is no rheumatologist practicing in this area. This community successfully participated in a pilot study in which the COPCORD core questionnaire was developed and validated in a sample of 200 subjects (14).

### Subject selection

A sample size calculation was made considering a 36% prevalence of musculoskeletal complaints with a 2% uncertainty level. It was estimated that 2213 subjects would be needed but finally 2500 were interviewed. A census updated in 1992, having name,

gender and addresses was used to generate a stratified (age and gender), balanced and random sample of subjects older than 18 years old in order to have a representative proportion of adult population in that community. If the selected subject was not at home, up to five attempts were made to interview this subject. If the potential participant was not located after these attempts, another subject living at the same home or street, with the same gender and decade of age was selected to replace those individuals.

#### *The instrument*

The COPCORD core questionnaire validated against physical examination, developed by a multidisciplinary team was used (14). It has shown a sensitivity of 84% using the definition of pain in the last seven days or ever and no trauma. If pain 4 is added to definition 1, specificity is 80.2%. It has the following sections: an explanation, demographic information, pain in the last seven days, pain ever, location in a mannekin, pain severity in a VAS (0-10), duration of pain, disability measured by the modified HAQ in which squatting and kneeling were incorporated (25), help seeking behavior with a comprehensive list of options; perceived efficacy and coping information.

#### *The interview*

Participants were visited at home and personally informed about the purpose of the interview. Three trained interviewers independently applied the questionnaire, two of them had previous experience in the pilot study (14) and a third one was hired and she had a supervised training for this study. All subjects who were receiving any treatment, provided additional information on type of treatment, why they selected that option, previous experience with that option, costs and perceived efficacy. All subjects who obtained a prescription also provided information about the type of medications, duration of treatment, costs and supervision of side effects. When available, the interviewers asked subjects to show their prescription or the medications to reg-

ister the generic formula of products. In cases of self-medication or use of non-conventional therapy, subjects were asked about the reasons for that selection, perceived severity, efficacy and costs of treatment.

#### *Medical evaluation*

This was done by a physician unaware of questionnaire results. He had been in training with a rheumatologist in an outpatient clinic for 8 months. He was asked to do an structured clinical interview and physical examination to all subjects with the case definition criteria, as follows: a) pain in the last seven days or in the past without trauma and pain severity 4/10; or b) current or past disability obtained by self report. This medical evaluation was done the same day of the interview in the great majority of cases. Only few cases were seen in the next days but always within a week after the questionnaire was applied. A sample of subjects without case definition criteria was also blindly evaluated for quality control. If needed, he had the possibility to order laboratory or X rays evaluations to establish a diagnosis and to consult a rheumatologist if clinically required. All detected cases were classified following American College of Rheumatology classification criteria when available (26-29). In cases of soft tissue rheumatism clinical criteria were followed. All patients received an advice, a prescription or a referral as appropriate. For ethical reasons, when inadequate treatment was detected, it was suggested that a second opinion be sought.

#### *Statistical analysis*

Prevalence of musculoskeletal complaints, disability and help seeking behavior using descriptive statistics among age and gender groups. Subgroup analysis of subjects seeking any treatment and subgroup description of patients with most common diagnoses such as osteoarthritis, low back pain, fibromyalgia, rheumatoid arthritis and gout to provide point prevalence estimates with 95% confidence intervals.

#### **Results**

A sample of 2500 subjects was interviewed: 53% were female (1,331) and 47% were male (1,169). The mean/SD duration of interviews was 6.4/5.2 minutes. Mean/SD age was 35/14 years old (min-max: 18 – 90 years). 21% were single and 63% were married. 96% described themselves with a working status, this category included 972 housewives (39% of the total sample). This sample is representative of the national characteristics of adult population registered in the 2000 National Census in terms of age and gender distribution (Table I).

*Pain in the last seven days.* 23% (585 subjects) described pain in the last 7 days. Of these 166 (28.4%) referred a recent trauma that could explain the pain. The most common sites with pain are described in Figure 1. Mean/SD pain score was 4.8/2.5 (in a 0-10 VAS). Mean duration of pain varied among sites and it had a skewed distribution. Median duration was 180 days in the knee; 60 days in the neck and 100 days in the shoulders. Prevalence estimates among age (10 years bands) and gen-

**Table I.** Main characteristics of sample in San Pedro Martir (1992) and the 2000 Mexican Census.

Variable	San Pedro Martir	2000 Census
Gender		
M/F (%)	47/53	49/51
% people > 20 years	49	53
% people > 65 years	5	5
% education > 6 years	87*	71**
% unemployed	1.8	2.1
% disability	1.4	0.8 (motor)

\* Percent of parents in the community with a level of education > 6 years.

\*\* Percent of people older than 15 years with a level of education > 6 years.

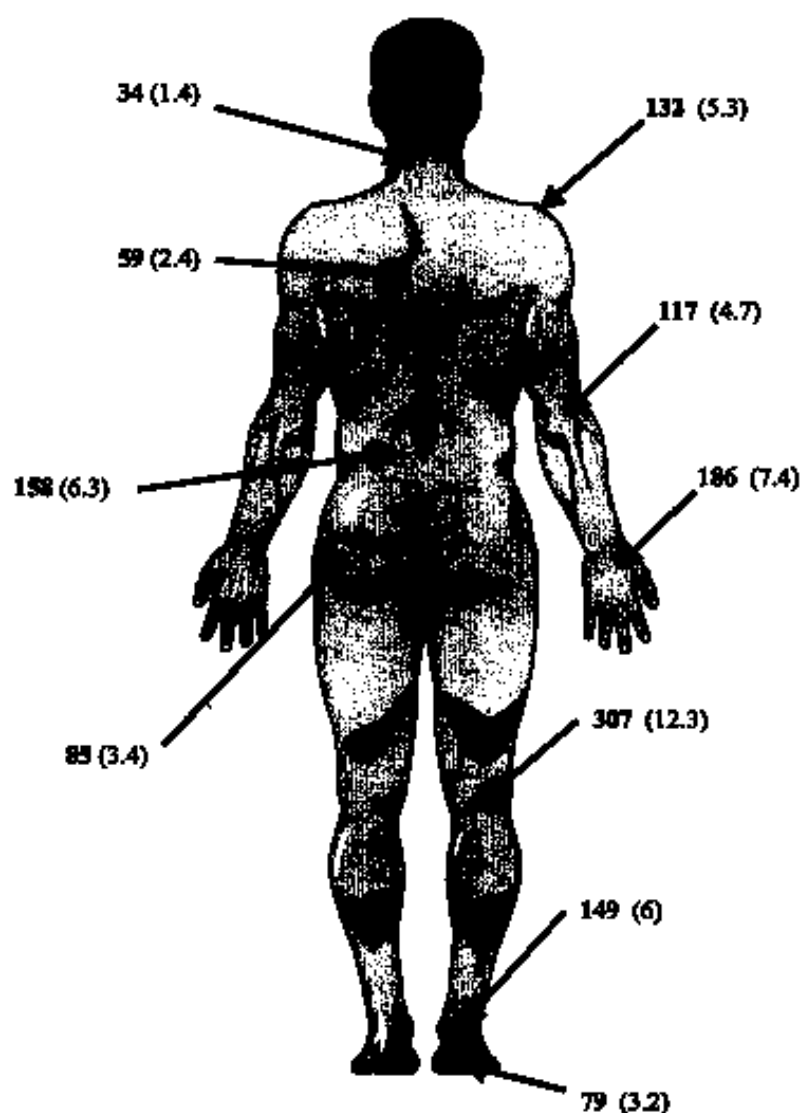


Fig. 1. Pain location in the last seven days n (%).

der is presented in Table II. Female subjects had a higher prevalence of pain 394/1331 versus 191/1169 in males [ $\chi^2 = 59.7$ ,  $p = 0.0001$ , OR 95% CI 2.1 (1.7-2.6)]. Pain site is presented in Table III, some sites were also statistically different in female subjects.

*Pain in the past.* 14% (334 subjects) had a musculoskeletal pain in the past and 128 (38.7%) was related to trauma. Most common sites are presented in Figure 2. Median/SD of pain score was 4.1/2.3.

*Coping.* Those subjects with pain in

the last 7 days or pain in the past answered an item on coping. 43 subjects (5%) described coping as "very well"; 568 (62%) as coping "well"; 261 (28%) as "not that well" and 49 (5%) "not coping at all".

*Help seeking behavior.* From a total of 919 subjects (37%) with musculoskeletal complaints, 348 (38%) had some type of treatment. Medical treatment prescribed by general practitioners was the most common (252 cases, 72%), followed by those prescribed in a general hospital in 41 (12%); rheumatologist in 16 subjects (4.5%), self medication in 16 and natural healers in 14 cases. 267 subjects received treatment with medications (29%). Of those, 200 said that they improved (75%) and 40 (15%) described side effects. Reasons for selection were: pain severity in 59 subjects; have an affiliation in 58 cases; a low cost was mentioned by 42 subjects; previous positive experience was described in 35 and recommendation was reported by 30 subjects.

*Disability.* Of those subjects who described pain in the last seven days or pain in the past, 35 subjects or 1.4% of the total sample described themselves as currently limited. (95% CI 0.9 – 1.9%). Mean/SD modified HAQ score was 0.2/0.3 with a skewed distribution, the 75 percentile was 0.2. Of the total sample 183 (7.3%) described themselves as limited in the past and 704 with musculoskeletal complaints (28% of the total sample) described themselves as never been limited.

*Predictive variables of seeking treatment.* 270 subjects sought some kind of treatment. Variables associated with a help seeking behavior were older age (mean/SD) (45/16 versus 36/14 years old;  $p = 0.0001$ ); higher pain scores in the last seven days (5.4/2.6 versus 3.5/1.9;  $p = 0.007$ ) and higher disability scores measured by modified HAQ (0.45/0.5 versus 0.18/0.33;  $p = 0.000$ ).

*Structured interview.* 301 subjects had an structured interview. Fourteen subjects without a positive screening definition were blindly evaluated in a quality control process. 175 (61%) of those screened positive had a rheumatic diagnosis by the clinician. Main diagnoses are presented below, it is impor-

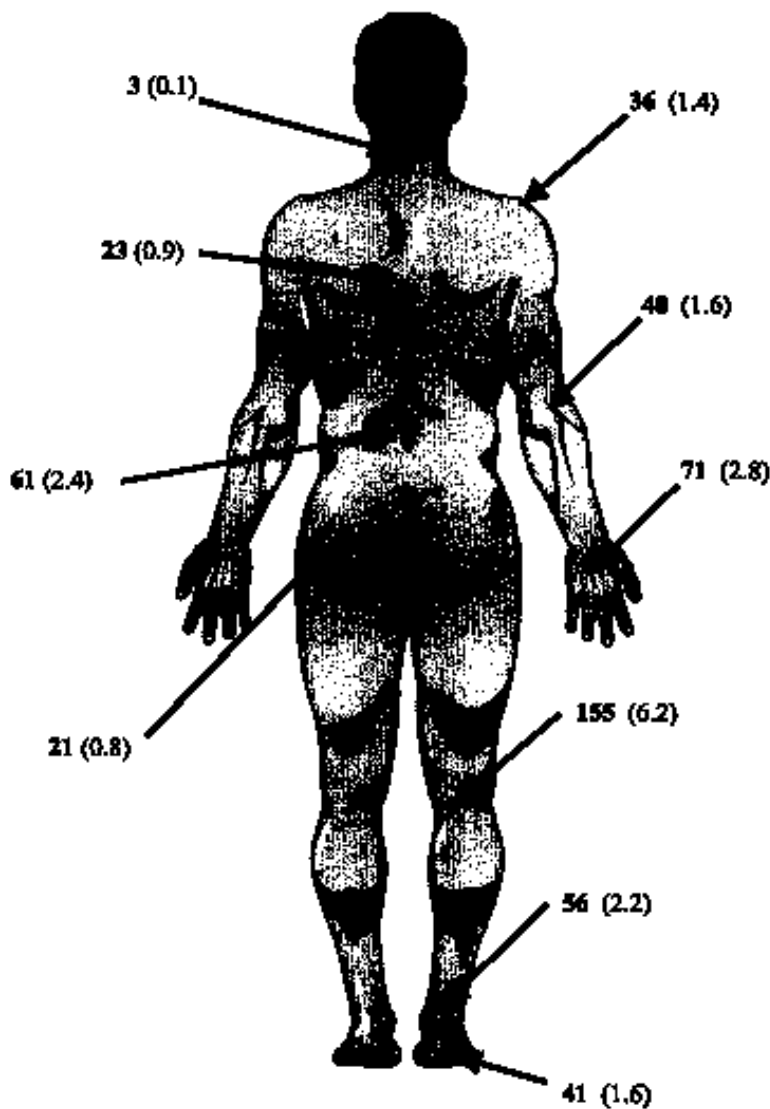
Table II. Pain in the last seven days.

Age	Male (1169) n/total (%)	Female (1331) n/total (%)	Total
18-25	34/335 (10%)	67/342 (20%)	101/677 (15%) ( $p=0.001$ )
26-35	37/340 (11%)	93/410 (23%)	130/760 (17%) ( $p=0.0001$ )
36-45	46/250 (18%)	90/273 (33%)	136/521 (26%) ( $p=0.0001$ )
46-55	30/119 (25%)	60/148 (41%)	90/267 (34%) ( $p=0.01$ )
56-65	19/67 (28%)	44/88 (50%)	63/155 (40.6%) ( $p=0.01$ )
66-75	13/39 (33%)	30/49 (61%)	43/88 (48.8%) ( $p=0.1$ )
> 76	9/19 (47%)	11/20 (55%)	20/39 (51.2%) ( $p=0.8$ )

**Table III.** Pain location in the last seven days.

	Neck	Hands	Shoulder	Elbow	Knee	High back	Low back	Hip and thighs
Age	M F	M F	M F	M F	M F	M F	M F	M F
18 - 25	0 - 1	3 - 15	5 - 6	0 - 7	13 - 28	4 - 5	6 - 22	2 - 4
26 - 35	3 - 2	4 - 32	7 - 17	2 - 12	13 - 38	4 - 10	6 - 30	3 - 13
36 - 45	3 - 6	14 - 44	10 - 23	7 - 27	18 - 45	4 - 12	7 - 32	3 - 15
46 - 55	1 - 7	6 - 23	8 - 13	5 - 21	18 - 35	4 - 5	8 - 10	4 - 10
56 - 65	1 - 7	4 - 22	2 - 22	5 - 16	14 - 29	1 - 6	4 - 11	5 - 6
66 - 75	1 - 2	3 - 8	2 - 8	3 - 7	8 - 27	0 - 3	2 - 9	2 - 8
> 76	0 - 0	3 - 3	1 - 5	2 - 2	6 - 7	2 - 0	2 - 1	1 - 3

Note: The total number is not exactly the same for the hands, shoulder, knee, lower back, hip and thighs due to 2.4% inconsistencies among the mannequin and specific description of the pain site by respondents.

**Fig. 2.** Pain location in the past n (%).

tant to mention that two cases with ankylosing spondylitis and no case with systemic lupus erythematosus were detected.

*Most common diagnoses.* The most frequent diseases and their characteristics are presented with the following objectives. To know a point prevalence

estimate, describe main characteristics in terms of pain severity, disability, help seeking behavior, and coping of osteoarthritis, fibromyalgia, low back pain, gout and rheumatoid arthritis. Comparative characteristics among diseases are presented in Table IV and Table V.

I. Osteoarthritis. This diagnosis can only be applied to subjects with symptomatic OA with a pain score 4 in a 0-10 pain scale or subjects who described current or past disability. These subjects also needed a clinical and some of them a radiologic evaluation. Fifty-eight subjects had this diagnosis, 2.3% of the general sample (95% CI 1.7 – 2.9). This estimate varied among decades, being 16/1125 cases (0.7%) in younger than 50 years old; and 42/375 (11%) in older than 50 years of age. 71% were female. Forty-nine or 84.5% described pain in the last seven days and nine subjects described a relationship with trauma. Pain severity was described with a mean/SD of 5.8/2.2. Most frequent pain sites were knee in 44, hand in 29, feet 24, back pain in 21, shoulders in 12 and hip in 9. Current disability was described in 7% and 30% described themselves as limited in the past. The mean/SD duration of disability was 86 days/SD 198 days. The mean HAQ-Di was 0.4. Almost half of these subjects (27 or 46.6%) were treated by the general practitioner; 2 subjects went to a hospital; 4 (6.9%) were seen by a rheumatologist; 1 had acupuncture and 5 (8%) referred self-medication. Thirty-four (58.6%) received a medication and 25 (73%) described an improvement. The mean duration of treatment was three months. Side effects of medications were described by 9 subjects (26%). Only 26 subjects (44%) had a diagnosis. Coping was described “well” by 35 subjects (61%); “not that well” by 20 (35%) and “not at all” by 2 (3.5%). Comorbidity. Diabetes mellitus and high blood pressure were also described by two patients each. The mean height was 1.58 m and the

**Table IV.** Prevalence of most common diseases. Gender distribution, pain and disability.

Disease (n)	Prevalence (95% CI)	Gender (M/F)	Pain (m/SD)	HAQ
Osteoarthritis (58)	2.3 (1.7 - 2.9)	41/17	5.8/2.2	0.4
Fibromyalgia (35)	1.4 (1.0 - 2.0)	0/35	7.1/2	0.4
Low back pain (158)	6.3 (5.4 - 7.3)	114/44	5.2/2.5	0.3
Rheumatoid arthritis (8)	0.3 (0.1 - 0.6)	2/6	8/2.5	1.0
Gout (10)	0.3 (0.1 - 0.7)	8/0	5.3/2.4	0.5

**Table V.** Help seeking behavior, perceived efficacy and coping characteristics.

Disease	GP	Self-med	Efficacy	Not Coping well
OA	46%	8%	73%	38.5%
FM	54%	32%	62%	61.8%
LBP	82%	12%	67%	45%
Gout	50%	20%	70%	70%
RA	50%	25%	75%	50%

GP: general practitioner

Self-med: self-medication

Efficacy: perceived efficacy

Not coping well: includes not coping well and not coping at all

OA: osteoarthritis; FM: fibromyalgia; LBP: low back pain; RA: rheumatoid arthritis.

mean weight was 67 kg; mean BMI = 27 kg/m<sup>2</sup>.

II. Fibromyalgia. The clinical diagnosis was established following ACR criteria (28). 37 cases were identified, a point prevalence estimate of 1.4% (95% CI 1.0 – 2.0). If only women are considered, 35 cases were seen in 1331 subjects. Point prevalence 2.6 (95% CI 1.8 – 3.6). All were female, age: mean/SD 38.4/11.2 years. Thirty-three described pain in the last 7 days, mean/SD severity 7.1/2. Only 3 described pain in the past with a mean severity of 7. Current disability was described by 2 patients; disabled in the past was mentioned in 19 (51.4%) and 16 (43.4%) described as never disabled. The mean HAQ-Di score was 0.4 in 27 subjects who filled out the questionnaire. Treatment was given by a general practitioner in 19 cases; pharmacist in one subject and self-medication was reported in 8 cases (32%). Medications were used in 16 subjects, ten of them reported efficacy (62%) and 3 described side-effects. Only 13 (37%) had a diagnosis, but 12 subjects had another diagnosis such as “rheumatism” in 2; rheumatic fever in one; menopause in 2, among

others. 38% described themselves “coping well”; 51% as “not that well” and 10.8% as “not at all”.

III. Low back pain. This was defined by self report. Only cases reporting low back pain in the last week are analyzed. 158 cases were detected or 6.3% (95% CI 5.4 – 7.3). 72% were female and 65% were married. Sixty-one cases or 39% described a trauma associated with the pain. The most frequently reported was a fall in 30 cases. Pain severity was mean/SD 5.2/2.5. Mean duration of pain was 6 months. 48% had some kind of treatment. The general practitioner treated 66/76 (82%) cases of those cases. Self-medication was reported in 9 cases (12%); two patients were treated by rheumatologists. Older age was a variable associated with help seeking behavior (43 versus 37 years old;  $p = 0.023$ ). Associated disability was 5.1% as currently disabled. Mean HAQ-Di scores were 0.3. Coping was described as very well in 6%; well in 49%, not that well in 37% and not at all in 8%.

IV. Gout. A clinical diagnosis was established if convincing clinical data was available. We did not confirm the diagnosis with microscopic evi-

dence of crystals. Ten cases were detected. A general prevalence of 0.4 in 100 subjects (95% CI 0.1 – 0.7). All cases were male, so in males a point prevalence estimate was 0.8% (95% CI 0.4 – 1.5). Mean age/SD was 49.8/ SD 11.8. Seven described pain in the last 7 days, two of them associated with trauma. Pain severity had a mean/SD: 5.3/2.4. Three described pain in the past, mean pain score 4.5. Two subjects described current limitation and 7 described limitation in the past. The median duration of limitation was 4 days. The mean HAQ-Di score was 0.5, SD 0.4. These patients were treated by the general practitioner in 5 cases; in a hospital in 1; a natural healer in 1; self medication in 2 cases. In 7 cases medication was prescribed, all these subjects described that it helped. Five subjects received diet instructions that were not followed. In 5 subjects treatment was only given for acute gout attacks, one described side effects. Seven subjects had a diagnosis established. Only 3 said that they were coping well; 5 not that well and 2 nothing well.

V. Rheumatoid arthritis. The diagnosis was established using the ACR classification criteria (29). Only those cases with current or pain in the past 4; with current or past disability could be detected by this strategy. Eight cases had this diagnosis, prevalence 0.3 cases per hundred (95% CI 0.1 – 0.6). The highest prevalence was found in female subjects, six cases were identified with point prevalence of 0.4 (95% CI 0.1 - 0.9). Mean age/SD: 45.2/ 16.5 years. All of them were working. Six subjects described pain in the last seven days. Mean/SD pain score was 8/2.5. One subject was currently limited and 3 were limited in the past. The mean duration of limitation in these 4 subjects was 318 days. Mean/SD HAQ-Di scores were 1.05/SD 0.7 (min-max 0.1-2.5). General practitioner treated 5 subjects; the rheumatologist treated 3 subjects. None of them received physiotherapy. Six had some med-

ication, 4 of them mentioned that they helped. Only one patient received instructions of a permanent treatment. The others interpreted it as a symptomatic objective. Six knew their diagnosis. Four subjects were not coping well and 1 not at all.

Other diagnoses captured by the questionnaire being not rheumatic disorders. Fourteen subjects without positive screening were sent to have an structured clinical interview. None of them had a rheumatic diagnosis by the clinician. Since pain and disability are the core element of this screening questionnaire, some diseases with these symptoms were detected and sent to clinical evaluation. The most common were: diabetes mellitus in four cases; thirteen cases with symptomatic venous insufficiency in lower limbs; nine cases with nonspecific muscular pain, postherpetic neuralgia in 1; brain vascular accidents were detected in two subjects.

## Discussion

This community based study showed that prevalence of musculoskeletal complaints in the last seven days was high (17%) and approximately half of these subjects had some treatment. Female subjects reported pain more frequently, an interesting and consistent finding among studies (3,12,13, 17) that would require additional research for a good explanation.

Factors associated with a help seeking behavior were age, pain severity and associated disability. Similar findings have been reported in a geriatric population in a health care plan (30) in which patients with musculoskeletal episodes were more likely to have formal treatment with higher age; higher perceived severity and frailty and those with limitations.

The general practitioner was the most frequently sought option. Self medication and alternative medicine was not commonly used. This may be due to a highly medical educated community where formal resources are available and the community has had previous positive experiences with formal treatment through several community

health programs done by the Department of Infectious Diseases from our institution (21-24).

It is important to contrast our results with other COPCORD studies (10-13, 16, 18-20) and a recently reported study in Spain (3). Regarding other COPCORD studies, it is important to emphasize the high participation rate in all COPCORD studies. Some figures are 95% in Urban population in Indonesia (13); 98% in Phillipines (12) and 99% in Thailand (18). Our study has some particular features, such as the urban population; the unique medical educated community; the stratified sample using updated census and the close physical examination after questionnaire application. These characteristics tend to improve precision in diagnostic detection and reflect a very atypical help seeking behavior with a very low rate of self medication or use of non conventional therapy. Nevertheless it is important emphasizing that treatment by a rheumatologist was very uncommon even in diseases such as rheumatoid arthritis.

A national survey done in Spain (3) showed similar prevalence of rheumatoid arthritis (0.5% in Spain and 0.3% in Mexico). A similar number (0.5%) was described in India (10) and it is stated that this was the highest prevalence found in rural Asian COPCORD studies. Fibromyalgia was reported in 2.4% in Spain and 1.4% in Mexico. Our study showed lower prevalence for osteoarthritis (knee OA 10.2% in Spain and 2.3% of OA in Mexico) and low back pain (14.8% in Spain versus 6.3% in Mexico). These last findings could be related with sample characteristics, only 5% of our sample was older than 65 years old against roughly 20% of their sample.

Our study has some limitations that we need to point out. Those subjects with pain < 4 would not be detected as cases. Nevertheless it seems clear that this screening methodology will detect all clinically relevant diagnosis associated with pain and disability. This might explain some discrepancies such as a point prevalence estimate of osteoarthritis of 2.3% but a knee pain was detected in 12.3%. A similar finding

was reported by Chopra in a rural population in Western India (10). He described that 240 subjects (5.9%) in their sample had chronic knee pain without evidence of knee osteoarthritis. An underestimation of some diagnoses is possible but probably clinically irrelevant. This has to be tested with another costly methodology.

It should be carefully evaluated if these estimates can be generalizable to adult Mexican population. It seems that the high quality of the sample selection and similarities with an updated national census can be taken as very close approximation of the national Mexican population. These findings could be applicable to prevalence estimates across the country with special concerns of Native groups and certainly limited in describing help-seeking behavior.

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