Chronic Joint Symptoms and Prior Arthritis Diagnosis in Community Surveys: Implications for Arthritis Prevalence Estimates

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SYNOPSIS

Objectives. Alternative definitions of arthritis in community surveys provide very different estimates of arthritis prevalence among older Americans. This telephone interview study examines prevalence estimates based on the current Behavioral Risk Factor Surveillance System (BRFSS) arthritis case definition.

Methods. Interviews were conducted with 851 Chicago residents age 45 and older. Logistic regression was used to compare the age and sex controlled prevalence of poor health, restricted activity, and arthritis risk factors among those with a previous arthritis diagnosis from a health professional, those with undiagnosed chronic joint symptoms, and those who were joint symptom free and without a previous arthritis diagnosis.

Results. BRFSS-defined arthritis prevalence was 47% of older residents, including 33% reporting a previous arthritis diagnosis and 14% chronic undiagnosed joint symptoms. Only 25% of these respondents reported current arthritis treatment by a doctor. After controlling for age and sex, respondents with a previous arthritis diagnosis and those with undiagnosed chronic symptoms had significantly worse health and functioning, and more prevalent arthritis risk factors, than respondents without joint symptoms.

Conclusions. BRFSS-defined arthritis included almost half the area population over age 45. Both diagnosed and undiagnosed chronic joint symptoms are associated with major functional limitations and arthritis risk after controlling for age and sex. The inclusion of previously undiagnosed chronic joint symptoms in the BRFSS arthritis definition is appropriate and indicates that previous arthritis prevalence estimates may be too low.

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Musculoskeletal pain is one of the major causes of the progression of functional limitations among the elderly.[1] A Canadian study reported that arthritis was the major cause of more than 30% of mobility and agility disabilities in the older population.[2] Arthritis accounted for 744,000 hospitalizations and 44 million ambulatory care visits in the United States in 1997, and utilization of prescription medications and alternative medicine for arthritis treatment continues to grow rapidly.[3] Projections based on the aging U.S. population indicate a doubling of the number of Americans living with chronic arthritis or rheumatic conditions by 2020.[4,5] Yet this prevalence estimate may be too conservative, and clearly depends on how arthritis—a constellation of over 100 separate rheumatic diseases or conditions affecting the joints—is characterized in population-based surveys.

Self-reported arthritis prevalence among older Americans is certainly far higher than could be inferred from clinical studies based on radiographic evidence or single joint disease.[6,7] Using the National Center for Health Statistics National Health Interview Study (NHIS) data classified by arthritis ICD-9-CM codes, Helmick et al. calculated that there were almost 40 million Americans in 1990 with arthritis or other chronic rheumatic conditions, including almost half of Americans age 65 and older.[8] Of these, 18.4% listed arthritis as a major or contributing cause of activity limitation, and 84% had consulted a doctor about their joint symptoms. With the rapid aging of the U.S. population, this number was estimated to have grown to 43 million by 1997, including eight million Americans (3% of the U.S. population) estimated to have arthritis-related activity limitations.[9]

However, arthritis prevalence estimates vary greatly as a function of how undiagnosed chronic joint symptoms are defined and which area is surveyed.[10] Over the last several years, a number of state health departments have included new and evolving arthritis prevalence interview questions as part of the statewide Behavioral Risk Factor Surveillance System (BRFSS) conducted with the National Center for Chronic Disease Prevention and Health Promotion.[10] The BRFSS arthritis module has now defined arthritis prevalence to include joint symptoms (pain, aching, stiffness in or around a joint) not including the back or neck, which have persisted for three months or longer, or whether a respondent had "ever been told by a doctor or other health professional" that they "had some form of arthritis, rheumatoid arthritis, gout, lupus, or fibromyalgia."

This telephone interview study examines prevalence as defined by the current BRFSS arthritis module items. The survey was conducted with a representative sample of residents age 45 or older living in several diverse communities in an approximate 3 square mile area of downtown Chicago. Questions from NHIS were used to evaluate functioning, health status, and arthritis risk factor differences associated with BRFSS arthritis. Additional questions about joint pain and access to care were also used to compare respondents with chronic undiagnosed joint symptoms to those reporting a prior arthritis diagnosis by a health professional. Results provide an in-depth picture of the burden of arthritis on the older population, with significant implications for evaluating arthritis treatment and education programs with community survey data.

METHODS

Telephone interviews

Telephone interviews were conducted by the Northern Illinois University Center for Governmental Studies and Public Opinion Laboratory under the direction of investigators from the Rehabilitation Institute of Chicago and the Northwestern University Feinberg School of Medicine. Interviews were carried out in the winter of 2000–2001. A Spanish translation of the interview instrument was used for Spanish speaking households using fluent interviewers. Interviewers conducted interviews and entered responses at computer terminals using a computer-assisted-telephone-interviewing (CATI) system, which guides interviewers through branching logic screens. The study was approved by the Northwestern University Institutional Review Board.

The downtown Chicago Lakefront area

The telephone survey area included seven contiguous ZIP Codes in the Loop, Near North, Near South, and Lincoln Park neighborhoods of Chicago (Figure 1). In 2000, the area had an estimated population of 212,691, with 79,126 residents age 45 or older. Approximately 23% of residents were African American and 8% Hispanic. The median household annual income of area residents in 2000 was estimated as $58,354, with 32% of households earning under $35,000. All of the area population estimates for 2000 were obtained from Claritas demographic software estimates.[11]

Interview questions and instruments

All respondents were asked about their health status, days of poor physical or mental health or activity limitations, days of missed work for those employed, and difficulty level for intermediate or basic activities of daily living. Arthritis risk factors assessed included a

history of knee injury, childhood hip injury, heavy weight-bearing exercise, or a report of being overweight by more than 10 pounds. Among respondents with BRFSS-defined arthritis, health care access was assessed by questions regarding access to a usual source of care, a personal physician, and cost as a limiting factor when seeking health care. Finally, respondents who indicated that they were currently being treated for arthritis were asked additional questions about use of medical or alternative care and arthritis information sources.

Telephone interview sampling design

Sampling was carried out in two stages, using disproportionate stratification for household selection at the first stage. Two samples were fielded, one a random-digit-dialed (RDD) sample and the other a targeted, listed sample. Stratification for weighting and analysis was based on the listed status of the telephone number. One stratum consisted of listed households with an adult 45 years or older (that is, households that were in the listed, targeted database, whether they were fielded in the RDD sample or in the listed targeted sample), and the other of households not in the targeted listed sample. The requirement for the targeted listed household sample was that all households in the listed database in the area to be sampled had an equal probability of selection. The requirement for the RDD sample was that all residential telephone numbers in the area (including listed, unlisted, and unpublished numbers) had an equal probability of selection into the sample. Telephone numbers drawn in the RDD sample were checked against the targeted listed database and were coded as "listed" if found. The second stage of sampling occurred when an eligible household (with at least one adult 45 years of age or older) was reached, and when an adult 45 years of age or older was selected to be interviewed.

Figure 1. The Chicago Lakefront community area

SOURCE: Available from: URL: http://www.mapblast.com

Consent was requested at the beginning of each interview, and respondents were informed they did not have to answer any question that they did not want to. Interviewers made a minimum of 15 attempts on unresolved numbers to reach a household. Once an eligible household was reached, interviewers attempted to select a respondent 45 years of age or older and to reach the selected respondent. Interviewers scheduled appointments for convenient callback times, and made repeated attempts to reach a household in order to complete an interview. An experienced interviewer or a supervisor phoned potential respondents who had initially refused to participate, in order to attempt refusal conversion. If a selected respondent refused a second time, interviewers made no further attempts to complete the interview.

Weighting

Standard errors for prevalence estimates were calculated using SUDAAN software to correct for the effect of the sample design.[12] Initial stratum weights were adjusted for unequal probabilities of selection at the household level. A poststratification adjustment to the weight was calculated, using an eight by two grouping of age-sex categories. Stratum weights for the demographic groupings were constructed using the current 2000 population estimates for the sampled area obtained from Claritas. For the purposes of poststratification, a median substitution for age was used for 14 cases with age missing. All results presented as population prevalence estimates reflect the English- and Spanish-speaking population 45 years of age or older in the study neighborhood areas accessible by telephone.

Statistical analysis

T-tests for mean differences and chi-square tests of association for categorical variables were used to test the significance of differences using the final weight adjusted to sample size. Those with BRFSS-defined arthritis are compared to the "benchmark" group: respondents reporting no current symptoms and no previous arthritis diagnosis. A small number of respondents reporting current joint symptoms for less than three months are thus excluded from these analyses. Multiple logistic regression, including age and sex, was used to compare the prevalence of poor health status, functional limitations, and arthritis risk factors among the benchmark asymptomatic group and both the diagnosed and undiagnosed respondents with chronic joint symptoms.

RESULTS

Arthritis prevalence estimates

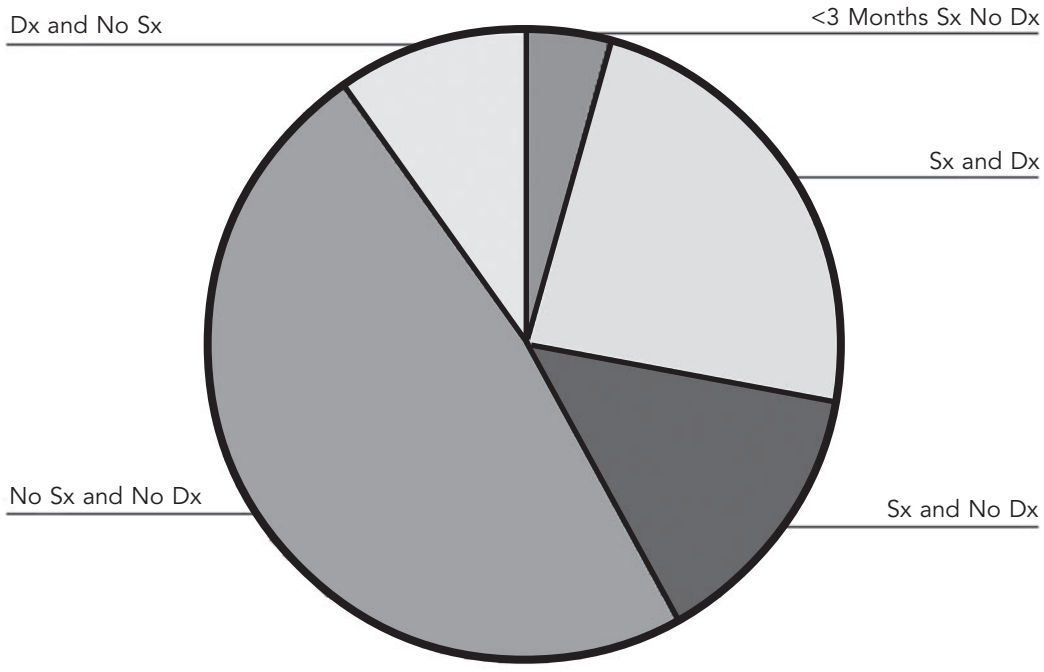
Interviewers at Northern Illinois University completed 851 interviews of downtown Chicago Lakefront Area residents from November 2000 through March 2001. Interviews took only an average of 10 minutes of respondents' time. These 851 observations were weighted to estimate arthritis prevalence for the estimated 79,126 Chicago Lakefront Area residents age 45 or older in 2000 (Figure 1).

Figure 2 displays the proportion of the total area older population that provided specific combinations of responses to the BRFSS arthritis module items on prior arthritis diagnosis, current and persistent joint symptoms. When those reporting current joint symptoms for more than three months are combined with those previously diagnosed with arthritis by a health professional, over 47% of all older residents were estimated to have BRFSS-defined arthritis.

Table 1 presents selected demographic characteristics of (1) residents who reported a previous arthritis diagnosis; (2) residents who reported chronic joint symptoms; (3) the overlap of these two groups, all those who reported BRFSS-defined arthritis; and (4) residents reporting no prior arthritis diagnosis and no current joint symptoms. The total community population includes the additional 4.4% of respondents who reported current joint symptoms, but for less than three months, and who were without a previous arthritis diagnosis. They are thus excluded from the BRFSS arthritis case definition.

As can be seen in the third column of Table 1,

Figure 2. Distribution of age >44 area population by combinations of BRFSS arthritis module items



Sx = joint symptoms >3 months

Dx = prior arthritis diagnosis by a health professional

Table 1. Demographic characteristics of respondents with BRFSS-defined arthritis vs. those reporting no current joint symptoms and no prior arthritis diagnosis

	Previous arthritis diagnosis	*>3 months joint symptoms and no previous arthritis diagnosis*	*Previous arthritis diagnosis or >3 months joint symptoms*	*No arthritis diagnosis or joint symptoms*	*Total community population age 45 or older*
Estimated area residents age >44	26,163	11,312	37,475	38,150	79,126
Area 2000 population[a]	33.1%	14.3%	47.4%	48.2%	100%
Male	37.2%	49.6%	41.0%	48.1%	44.7%
Female	62.8%	50.4%	59.0%	52.0%	55.3%
Mean age (SD)	64.1 (12.4)	57.3 (10.2)	62.0 (12.2)	59.3 (12.5)	60.6 (12.1)
High school education or less	17.0%	16.0%	16.7%	14.7%	15.8%

[a]Respondents reporting joint pain for >3 months and no previous arthritis diagnosis (4.4%) are included in total population.

SD = standard deviation

47.4% of all older residents were estimated to have either persistent, undiagnosed joint symptoms for three months or longer (14.3%) or to have been previously told they had arthritis by a health professional (33.1%). As expected, arthritis was associated with significantly older average age and a higher proportion of women. The lack of a large educational prevalence gradient does not reflect previously published national data.[13]

As compared with about 25% of all those with BRFSS-defined arthritis, 36.6% of respondents with a previous arthritis diagnosis (Table 1, column two) reported currently being treated by a doctor for their joint symptoms; 9% of these respondents indicated they had rheumatoid arthritis; and 31.5% indicated they didn't know what type of arthritis they had. Of all those reporting joint symptoms for more than three months, only 0.4% indicated that their joint symptoms were related to a recent injury.

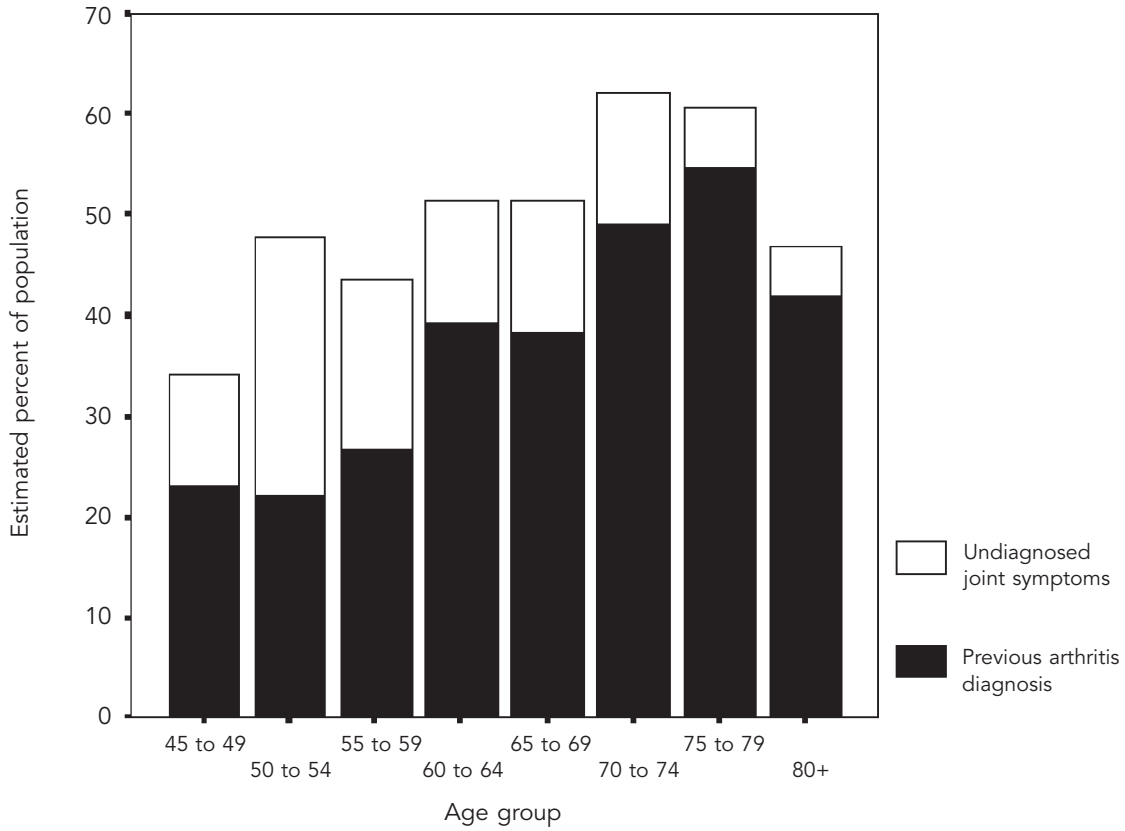
Figure 3 presents the estimated population percentages of previously diagnosed arthritis and undiagnosed persistent joint symptoms across eight older age groups. The prevalence of all BRFSS-defined arthritis peaks at about 60% for ages 70 through 79 and then levels off for those who have survived to age 80 or older (and are still able and willing to provide telephone interviews). The finding of lower arthritis prevalence among the oldest respondents in this survey is likely to be an artifact of telephone use among the non-institutionalized, urban elderly. Overall, 14.3% of older area residents reported undiagnosed persistent joint symptoms, which were not currently being treated.

Residents who had been told by a doctor they had arthritis but reported no aching, pain, or stiffness in upper and lower extremity joints in the past 30 days accounted for 9.8% of residents. This group actually includes a quarter of all those reporting a previous arthritis diagnosis. It is unknown the extent to which asymptomatic residents with a previous arthritis diagnosis reflect successful joint symptom treatment, the prevalence of back or neck symptoms that may have led to a previous arthritis diagnosis, or other factors.

Arthritis-associated health status, functional limitation, and risk factors

Table 2 presents selected health and functional conditions and arthritis risk factor prevalence. The table provides both univariate and age and sex adjusted multivariate tests of the significance of differences for each condition. Respondents with diagnosed and undiagnosed arthritis are separately compared to the benchmark group of older residents without a previous arthritis diagnosis or current joint symptoms. Results reveal a very significant burden of excess morbidity and functional limitation among older residents with a previous arthritis diagnosis, and to a lesser, but still very significant level, for those with persistent, undiagnosed joint symptoms. Age and sex adjusted odds ratios for measures of poor health or activity limitation indicated that residents with previously diagnosed arthritis were more than nine times more likely to report a difficulty with at least one activity of daily living, while residents with undiagnosed chronic joint symptoms were more than four times more likely to report a difficulty. Both groups included in the BRFSS arthritis case definition were significantly more likely to report fair to poor general health, more than

Figure 3. Proportion of the area population by age group with persistent (three months or longer) undiagnosed joint symptoms or a previous arthritis diagnosis by a health professional



five days of poor health in the last month, and being limited by health problems. Evidence in Table 2 about arthritis risk factor prevalence also indicates a significantly higher rate of prior knee injury and being overweight among both BRFSS-defined groups.

However, the less severe nature of undiagnosed arthritis is evident from results for those reporting more than five days of restricted activity in the last month, with this generally younger (mean age of 57) group of respondents reporting an even lower restricted activity rate than asymptomatic respondents. Undiagnosed residents were more likely to be employed (69%), and there were only small differences in the number employed in each group who reported missing 10 or more work days due to illness in the last year. As is expected from the literature on use of doctors for arthritis,[14] residents with persistent undiagnosed symptoms were more likely to be younger and female. The proportion of undiagnosed residents with joint symptoms diminished with age as would be expected if persistent symptoms lead to physician diagnosis over time.

On the other hand, undiagnosed residents did not have significantly lower mean (0 to 10) joint pain ratings than diagnosed residents, with 21.5% above a rating of five versus 27.0% of those with a previous arthritis diagnosis. Although 16.5% of diagnosed residents had pain ratings greater or equal to 8 on the 10-point scale, 11.5% of undiagnosed residents had similar ratings, which yields an estimate of over 1,200 area residents with severe undiagnosed joint pain rated as 8-point or higher. There were no significant differences among groups for joint symptom duration or location—both groups had approximately two-thirds reporting symptoms for more than one year, and just under half reporting more than five years of symptoms. Undiagnosed residents were significantly less likely to report having a personal doctor than diagnosed residents (19.7% vs. 11.0%; p=0.02), but other access factors were comparable.

Table 2. Health status, disability, and arthritis risk factors

Age and sex controlled logistic regression results comparing residents with previously diagnosed arthritis and undiagnosed chronic joint symptoms to residents without current joint symptoms or prior arthritis diagnosis.

	No arthritis diagnosis or joint symptoms	*Previous arthritis diagnosis*	*>3 months joint symptoms/no prior arthritis diagnosis*	*Age/sex adjusted odds ratio for arthritis diagnosis*	*Age/sex adjusted odds ratio for undiagnosed chronic joint symptoms*
	Percent	*Percent*	*Percent*	*Percent*	*Percent*
Health status and disability					
Limited "any way" by health problems	14.9	43.3[b]	30.6[b]	4.2[d]	2.6[d]
Fair or poor general health status	9.2	19.6[b]	20.5[b]	2.0[c]	2.8[d]
Greater than five days poor physical health last month	8.5	28.4[b]	16.4[a]	3.6[d]	2.1[c]
Any ADL difficulty	2.9	22.8[b]	10.7[b]	8.7[d]	4.2[d]
Any ADL or IADL "unable to do"	2.7	11.0[b]	2.5	3.6[d]	1.1
Greater than five days restricted activity last month	6.1	15.3[b]	4.9	2.3[c]	0.8
Employed with greater than 10 days missed work for pain/illness in the last year[e]	6.9	7.6	9.6	1.03	1.5
Arthritis risk factors					
Prior knee injury	11.0	31.2[b]	25.4[b]	3.8[d]	2.8[d]
Past of current heavy weight-bearing exercise	6.8	11.0[b]	12.3[a]	1.5	1.8
Childhood hip impairment	0.2	0.8	0.8	3.2[c]	5.1[c]
More than 10 pounds overweight	32.1	60.3[b]	50.4[b]	3.5[d]	2.0[d]

[a]Univariate chi-square test, separate comparison with no joint symptoms and no arthritis, $p<0.05$

[b]Univariate chi-square test, separate comparison with no joint symptoms and no arthritis, $p<0.001$

[c]Multiple regression including age and sex, $p<0.05$

[d]Multiple regression including age and sex, $p<0.001$

[e]Denominator based on those reporting current employment (47% of those with arthritis diagnosis, 69% with undiagnosed chronic joint symptoms and 60.2% of those with no joint symptoms).

ADL = Activities of Daily Living: bathing, dressing, eating, arising from bed, using a toilet, getting around the house

IADL = Instrumental Activities of Daily Living: preparing meals, shopping, managing money, using the telephone, heavy housework and light housework

Use of services, satisfaction and sources of arthritis information

Figure 4 presents data on various arthritis treatments and services being used by symptomatic residents being actively treated for their symptoms (about half of all those with BRFSS-defined arthritis). Respondents reported very high rates of satisfaction with most of these, although magnets and copper bracelets had the lowest ratings (66%), followed by creams (73%), over-the-counter medications (80%), and prescription medications (81%). Figure 5 presents current arthritis information sources used. As expected, doctors were most influential, followed by magazines and newspapers.

DISCUSSION

The telephone survey findings presented here indicate a much higher prevalence of joint symptoms than previously reported in older BRFSS or NHIS surveys. The most recently published NHIS findings indicate that the national prevalence of arthritis or rheumatic conditions increases sharply from about 30% for respondents ages 55 through 64 to about 45% to 46% for those ages 65 through 84, with a drop-off in prevalence among respondents in their 80s.[9] This may reflect the medically defined, ICD-9 coded checklist approach of the NHIS, for which back and neck problems are included, as opposed to the more inclusive extremity joint symptom items used in the BRFSS. The 1996 BRFSS data, based on the presence of joint symptoms for "most days of at least one month" with a one year symptom duration, indicated that there was almost a two-fold variation in prevalence estimates across the seven states surveyed.[10] The inclusion of undiagnosed chronic joint symptoms is likely to produce a much higher arthritis prevalence rate than found in previously published studies.[15] However, even the highest of these estimates was significantly lower than reported here, with approximately 31% of residents age 65 or older reporting chronic joint symptoms, as compared with more than 50% of Chicago respondents of the same age.

Figure 4. Treatments and services used for joint symptoms by area residents

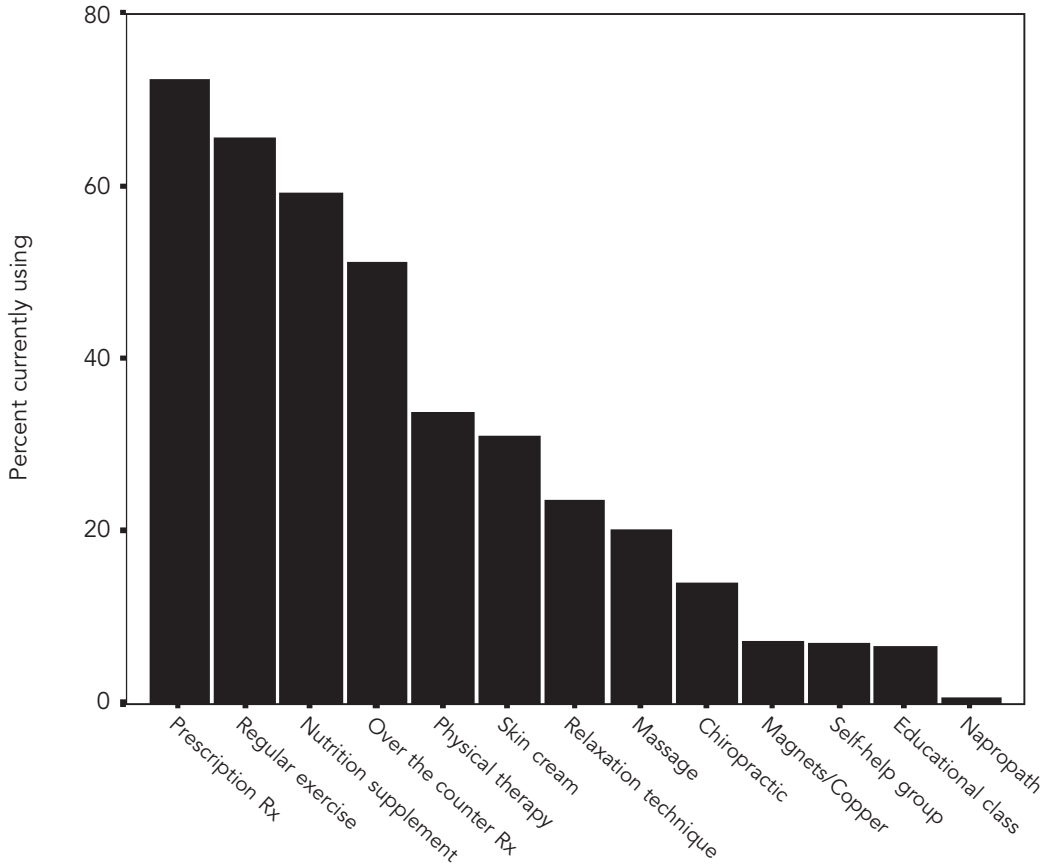
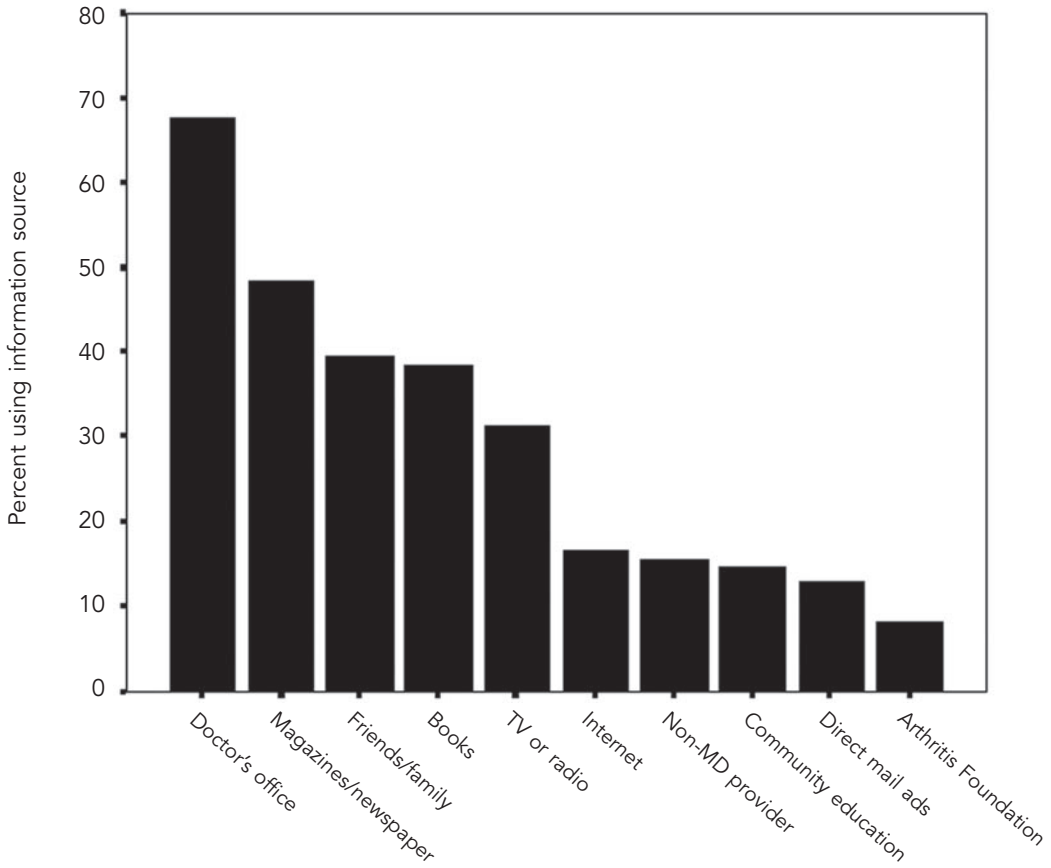


Figure 5. Arthritis information sources used by community residents



Some of the elevated arthritis prevalence may be associated with the relatively large low-income population in the downtown Chicago lakefront communities. For instance, there was an approximate 35% prevalence difference when arthritis rates were compared between the top and bottom fifths of family income in recent health tracking surveys of 60 U.S. metropolitan areas.[13] The NHIS, like most other studies, did find an age-adjusted female predominance and a (perhaps related) significant gradient of higher arthritis prevalence among respondents with less education and lower income.[8,9,14] However, there was a substantial proportion of high-income and college educated respondents to this survey, and the educational gradient in this Chicago sample was much less significant. Most of the higher prevalence reported here is much more likely to be a function of the new wording of BRFSS arthritis module items, and, specifically, of including those with more than three months of joint symptoms, regardless of whether these individuals had been diagnosed with arthritis by a health professional.

These results indicate that it is justified to include both untreated and undiagnosed individuals with chronic joint symptoms in the arthritis case definition. According to 1990 NHIS data, 16.5% of those with self-reported arthritis or another rheumatic condition (an estimated six million Americans in 1990) had not seen a doctor for their symptoms in the last year.[16] Rao et al. found that these non-users of physician services were largely (84%) insured, and most (72%) reported seeing a doctor for a different health problem in the previous year. BRFSS state data indicate that about 40% of respondents with chronic joint symptoms had not been told by a doctor they had arthritis, less than half reported being treated by a doctor for arthritis, and from 30% to 50% were told by a doctor they had arthritis, but could not name the type of arthritis they had.[10] An even larger proportion of Chicago Lakefront Area residents (43%) with persistent joint symptoms

had never been told by a doctor or other health professional that they have arthritis, and a third who had been told did not know what kind. These findings represent a large missed opportunity for cost-effective arthritis education and treatment.[17,18]

As indicated by the use of services and sources of information reported in this survey, an alliance of area physician offices with community arthritis advocates offers the best possibilities for reaching currently undiagnosed or uneducated populations with joint disease in large urban areas such as Chicago. An alliance of area physician offices with community arthritis advocates would go a long way in encouraging people with joint pain, especially younger women and those without a current regular doctor, to seek treatment. Since many people with severe joint symptoms do not have a personal physician, it is even more critical that public health agencies and community-based clinics become involved in arthritis education. The common need for concurrently run professional education and self-management programs may also be implied from the similarities in symptom duration between those with and without an arthritis diagnosis.

If performed sequentially in the same areas, relatively efficient, low-cost telephone surveys can provide valuable on-going measures of progress for arthritis education, treatment, and prevention programs. Researchers wishing to evaluate the public health impact of new arthritis management strategies will have to agree on specific measures of arthritis prevalence that include the millions of Americans with currently undiagnosed or untreated joint disease.

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