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Estimates of the Prevalence of Arthritis and Other Rheumatic Conditions in the United States

Part I

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Objective. **To provide a single source for the best available estimates of the US prevalence of and number of individuals affected by arthritis overall, rheumatoid arthritis, juvenile arthritis, the spondylarthritides, systemic lupus erythematosus, systemic sclerosis, and Sjögren's syndrome. A companion article (part II) addresses additional conditions.**

Methods. **The National Arthritis Data Workgroup reviewed published analyses from available national surveys, such as the National Health and Nutrition Examination Survey and the National Health Interview Survey (NHIS). For analysis of overall arthritis, we used the NHIS. Because data based on national population samples are unavailable for most specific rheumatic conditions, we derived estimates from published studies of smaller, defined populations. For specific conditions, the best available prevalence estimates were applied to the corresponding 2005 US population estimates from the Census Bureau, to estimate the number affected with each condition.**

Results. **More than 21% of US adults (46.4 million persons) were found to have self-reported doctor-diagnosed arthritis. We estimated that rheumatoid arthritis affects 1.3 million adults (down from the estimate of 2.1 million for 1995), juvenile arthritis affects 294,000 children, spondylarthritides affect from 0.6 million to 2.4 million adults, systemic lupus erythematosus affects from 161,000 to 322,000 adults, systemic sclerosis affects 49,000 adults, and primary Sjögren's syndrome affects from 0.4 million to 3.1 million adults.**

Conclusion. **Arthritis and other rheumatic conditions continue to be a large and growing public health problem. Estimates for many specific rheumatic conditions rely on a few, small studies of uncertain generalizability to the US population. This report provides the best available prevalence estimates for the US, but for most specific conditions, more studies generalizable to the US or addressing understudied populations are needed.**

In adults, arthritis is the leading cause of disability (1) and is among the leading conditions causing work

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limitations (2). Over the next 25 years the number of people affected and the social impact of doctor-diagnosed arthritis are projected to increase by 40% in the US (3). Estimating the burden in the US population of the various rheumatic conditions that comprise arthritis is important for understanding their current and potential future impact on the health care and public health systems. Equally important is identifying the gaps in our understanding of burden.

This and a companion article (4) update the National Arthritis Data Workgroup (NADW) reports of arthritis prevalence, our measure of burden, from 1989 and 1998 (5,6). Sjögren's syndrome and carpal tunnel syndrome have been included for the first time, and additionally, the common symptoms of neck and back pain are addressed.

METHODS

The term "prevalence" has been defined and used in conflicting ways. In these 2 articles, we use prevalence to mean "prevalence proportion" (incorrectly called "prevalence rate" at times), meaning the proportion of persons in the population with the condition. We use the phrase "number affected" to refer to the absolute number of people affected in the population.

US estimates of disease prevalence were usually based on data from published national or local population-based studies from the US and, if no accurate US data were available, from international studies. For overall arthritis, the number affected was based on the population sampled in the 2003–2005 National Health Interview Survey (NHIS). For other conditions, the best available prevalence estimates were applied to the corresponding July 1, 2005 population estimates from the Census Bureau (http://www.census.gov/popest/national/asrh/NC-EST2005-sa.html) to estimate the number affected. Some of the US population-based studies were special studies in small areas that may not reflect the racial and ethnic profile of the US or of those affected by the illness. Caveats accompany the estimates presented, when there are concerns about generalizability.

Several estimates came from 2 National Center for Health Statistics surveys: the NHIS and the National Health and Nutrition Examination Survey (NHANES). Both use probability samples of the US civilian, noninstitutionalized population to generate national health estimates. The NHANES uses interviews and examinations (e.g., physical examinations, laboratory tests, and radiographs) from ~5,000 respondents annually. The much larger NHIS uses an annual cross-sectional, in-person interview survey of ~106,000 respondents in 43,000 households to collect self-reported health status information. Estimates for overall arthritis obtained using the NHIS were age adjusted to the projected 2000 population age ≥18 years by 3 age groups (18–44 years, 45–64 years, and ≥65 years) to allow better comparison of demographic groups (available at http://www.cdc.gov/nchs/data/statnt/statnt20.pdf [used .530458, .299194, and .170271 from distribution 9, for ages 18–44, 45–64, and ≥65, respectively]).

Measuring the prevalence of arthritis poses many challenges. From study to study, the distinction between point prevalence and cumulative (i.e., lifetime) prevalence is not always clear. Prevalence is difficult to determine for conditions that are episodic. Some conditions have no standard case definition, whereas others have competing or evolving case definitions based on different symptoms, signs, radiographic findings, or laboratory data. Estimates vary depending on the inclusion or exclusion of asymptomatic, mild, or early disease and the aggressiveness of case finding. Symptomatic individuals in the community who do not seek treatment may go uncounted. Furthermore, individuals frequently do not know what specific rheumatic disease they have, so self-reported data cannot be used for estimates of specific conditions.

RESULTS

Overall arthritis. The case definition used to identify persons with arthritis has changed since our last report (6). In 1997 the NHIS stopped using condition lists and International Classification of Diseases, Ninth Revision, Clinical Modification (ICD-9-CM) codes, the basis of our previous method, and instead adopted new surveillance questions. Based on cognitive and validation studies (7,8), "self-reported doctor-diagnosed arthritis" is thought to provide the most credible estimate of overall arthritis prevalence, with acceptable sensitivity and specificity for surveillance purposes. Respondents were defined as having doctor-diagnosed arthritis if they answered "yes" to the question, "Have you EVER been told by a doctor or other health professional that you have some form of arthritis, rheumatoid arthritis, gout, lupus, or fibromyalgia?" Among those with doctor-diagnosed arthritis, activity limitation attributable to arthritis was defined by a "yes" answer to the question, "Are you now limited in any way in any of your usual activities because of arthritis or joint symptoms?"

The prevalence of self-reported doctor-diagnosed arthritis among adults age ≥18 years, estimated using the annual average from the 2003–2005 NHIS surveys, was 21.6%, or 46.4 million (9) (Table 1). Although arthritis prevalence was higher in older age groups, with half of adults age ≥65 years being affected, nearly two-thirds of the adults reporting doctor-diagnosed arthritis were younger than 65 (Table 1). More than 60% were women. Age-adjusted arthritis prevalence was higher for women than for men (24% versus 18%) but was similar for non-Hispanic whites and African Americans (~22%), whose rates were higher than those for Hispanics (16.5%). The number of persons with doctor-diagnosed arthritis is projected to

Table 1. Unadjusted and age-adjusted estimates of the prevalence of and number affected by self-reported doctor-diagnosed arthritis and arthritis-attributable activity limitations among adults age ≥18 years, by sex, age, and race/ethnicity, National Health Interview Survey, United States, 2003–2005*

		Doctor-diagnosed arthritis (46.4 million affected)		Arthritis-attributable activity limitation (18.9 million affected)		Proportion with arthritis-attributable activity limitation among those with doctor-diagnosed arthritis	
	Population, in 1,000's	Unadjusted % ± 95% CI (no. affected)	Age-adjusted % ± 95% CI†	Unadjusted % ± 95% CI (no. affected)	Age-adjusted % ± 95% CI†	Unadjusted % ± 95% CI	Age-adjusted % ± 95% CI†
Sex							
Men	103,362	17.6 ± 0.5 (18.2 million)	18.1 ± 0.5	6.8 ± 0.3 (7.0 million)	7.0 ± 0.3	38.8 ± 1.4	36.6 ± 1.8
Women	111,411	25.4 ± 0.6 (28.3 million)	24.4 ± 0.5	10.7 ± 0.3 (11.9 million)	10.3 ± 0.3	42.3 ± 0.9	39.0 ± 1.2
Age, years							
18–44	110,318	7.9 ± 0.3 (8.7 million)	–	2.7 ± 0.2 (3.0 million)	–	34.6 ± 1.9	–
45–64	70,019	29.3 ± 0.7 (20.5 million)	–	11.8 ± 0.4 (8.2 million)	–	40.3 ± 1.2	–
≥65†	34,435	50.0 ± 0.9 (17.2 million)	–	22.4 ± 0.7 (7.7 million)	–	44.9 ± 1.3	–
Race/ethnicity							
White, non-Hispanic	153,148	24.3 ± 0.5 (37.2 million)	22.6 ± 0.4	9.6 ± 0.3 (14.7 million)	8.9 ± 0.3	39.5 ± 0.9	36.4 ± 1.2
Black, non-Hispanic	23,775	19.2 ± 0.9 (4.6 million)	21.4 ± 0.9	9.2 ± 0.6 (2.2 million)	10.3 ± 0.7	47.8 ± 2.4	44.3 ± 3.2
Hispanic	26,904	11.4 ± 0.6 (3.1 million)	16.5 ± 0.8	5.4 ± 0.4 (1.5 million)	8.2 ± 0.6	47.6 ± 2.6	45.2 ± 3.2
Other non-Hispanic	10,946	14.7 ± 1.3 (1.6 million)	17.3 ± 1.3	6.0 ± 0.8 (0.66 million)	7.2 ± 1.0	41.1 ± 4.8	40.5 ± 5.4
Total	214,772	21.6 ± 0.4	21.5 ± 0.4	8.8 ± 0.2	8.8 ± 0.2	40.9 ± 0.8	38.1 ± 1.0

* See ref. 9.
† Adjusted to the projected 2000 population age ≥18 years by 3 age groups: 18–44 years, 45–64 years, and ≥65 years (see ref. 88). 95% CI = 95% confidence interval.

increase to nearly 67 million by 2030 (3)—an increase of ~40%.

Using the same report as was used to determine prevalence (9), we found that an estimated 8.8% of all US adults, or nearly 19 million persons, had arthritis-attributable activity limitations (Table 1). The prevalence of activity limitations was higher in older age groups (affecting >22% of all adults age ≥65 years), higher among women, and lower among Hispanics. Arthritis or joint symptoms led to activity limitation in >40% of adults with doctor-diagnosed arthritis. This outcome is projected to increase to 25 million (9.3% of the adult population) by 2030 (3).

The high population prevalence of arthritis and of arthritis-related activity limitations translates into an immense personal and societal burden, often differing by race/ethnicity (10). This situation results in "arthritis and rheumatism" being the leading cause of physical disability in the US (1) and causes affected persons to have a substantially worse health-related quality of life (11). Among various other impact/burden measures, arthritis and other rheumatic conditions in 1997 were the underlying cause of death in 9,367 persons in the US (12), were present in 300,000 nursing home residents (19%) (13), and resulted in 744,000 hospitalizations (14) and 36.5 million ambulatory care visits (15). Costs of arthritis and other rheumatic conditions in 2003 were $128 billion (16).

Rheumatoid arthritis (RA). RA is a multisystem disorder of unknown etiology, characterized by chronic destructive synovitis. Our previous national prevalence estimates for RA (6) were derived from the NHANES I, which used a case definition based on the clinical diagnosis by the examining physician. Since that time, classification criteria for RA have been revised (17–19).

Several studies have provided estimates of the prevalence of RA in defined populations. Although these studies had a number of methodologic limitations (20), the remarkable finding was the uniformity of prevalence estimates in populations from different de-

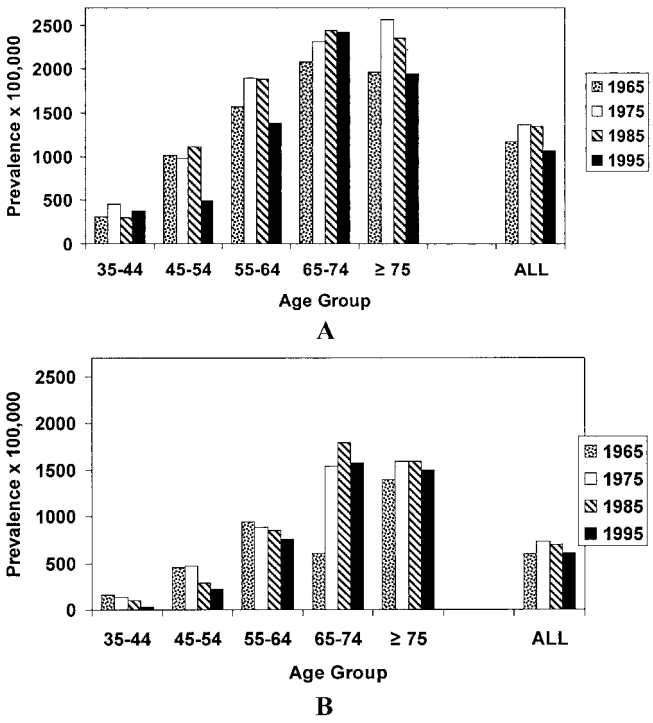

Figure 1. Prevalence of rheumatoid arthritis (adjusted to the 2000 white US population) among female residents (**A**) and male residents (**B**) of Rochester, Minnesota at 4 time points (1965, 1975, 1985, and 1995 [January 1 of each year]), by age group.

veloped countries: ~0.5%–1% of the adult population. However, studies from the Pima Indian population showed significantly higher incidence and prevalence estimates (21).

A study from Rochester, Minnesota showed a prevalence of RA in 1985 of 1.07% (95% confidence interval [95% CI] 0.94–1.20) among adults ≥35 years of age (22); this fell to 0.85% in 1995 (95% CI 0.75–0.95) (Gabriel S, et al: unpublished data). The prevalence among women in 1995 was approximately double that in men (1.06% versus 0.61%) (Gabriel S, et al: unpublished data).

Trends in RA prevalence in Rochester, Minnesota by age and calendar year show increasing prevalence with older age and decreasing prevalence for most age groups in more recent time periods (Figure 1). These trends, by calendar year, age, and sex, have also been demonstrated in numerous other populations (21–26). In particular, the temporal decline in RA prevalence is consistent with studies showing a progressive decline in RA incidence since the early 1960s (21,27–30). Also, the average age of persons with prevalent RA has increased steadily over time, from 63.3 years in 1965 to 66.8 years in 1995, suggesting that RA is becoming a disease of older adults. This observation, along with the expected rapid growth in the proportion of Americans age >60 years, suggests that RA-associated morbidity, mortality, and disability are likely to increase among older adults.

Using the 1995 Rochester, Minnesota age/sex-specific prevalence and the corresponding 2005 population estimates from the Census Bureau, we estimated that 1,293,000 American adults age ≥18 years (0.6%) have RA. This is lower than the previous estimate of 2,100,000 (6) because of the decline in RA prevalence. These Rochester estimates are likely to be generalizable to the white US population, but their generalizability to other racial/ethnic populations is uncertain.

Juvenile arthritis. The prevalence of chronic, inflammatory arthritis in children is difficult to estimate because of differences in nomenclature (e.g., "juvenile rheumatoid arthritis" [JRA], "juvenile chronic arthritis" [JCA], and most recently "juvenile idiopathic arthritis" [JIA]) and classification criteria (1977 American College of Rheumatology [ACR; formerly, the American Rheumatism Association] [31], 1978 European League Against Rheumatism [32], and 1997 International League of Associations for Rheumatology [33] with a revision published in 2004 [34]), and the heterogeneity of the diseases and their subtypes encompassed under this rubric (35). In addition, variability in disease course among the subtypes of JIA may make it difficult to compare prevalence estimates for this condition across different study settings. In some types of the disease extended remissions occur, so that prevalence estimates include individuals who were ever affected, but are not currently affected.

Prevalence reported in a comprehensive review ranged from 7 to 401 per 100,000 children across a broad diversity of geographic regions (35). Data from Rochester, Minnesota suggested declining prevalence, from 9.43 per 100,000 children in 1980 to 8.61 per 100,000 children in 1990 (36). These prevalences were lower than previous estimates from the same population, owing, in part, to differences in assignment of case definition.

The combined incidence of JRA and juvenile spondylarthritis ("spondylarthritis" being a more contemporary term for what is synonymously referred to in many earlier publications as "spondylarthropathy" [see below]) from other recent US and Canadian studies consistently ranges from 4.1 to 6.1 per 100,000, with the incidence of juvenile spondylarthritis ranging from 1.1 to 2 per 100,000 (37–39). These studies have encompassed

Table 2. Prevalence of spondylarthritides, overall and by subtype

Disease subtype	Group	Ref.	Prevalence per 100,000*		
			Male	Female	Total
Ankylosing spondylitis	Nationally representative (age ≥25 years men, ≥50 years women)	48	730	300	520
	Whites (age ≥15 years) men and women	46	200	70	130
	Blacks	47	50–200	NA	NA
	Eskimos (age ≥20 years)	53, 61	400	400	400
Psoriatic arthritis	Whites (age ≥20 years)	54			101
Enteropathic					
Peripheral		56, 57			65
Axial		57–59			50–250
Undifferentiated spondylarthritis		60, 61			374†
Overall spondylarthritides					346–1,310‡

* NA = not applicable.
† The undifferentiated spondylarthritis estimate was derived by multiplying the frequency of the other spondylarthritides by 40% (assuming the maximum estimate for enteropathic arthritis) ([520 + 101 + 65 + 250] × 0.4 = 374).
‡ The low range of overall spondylarthritides was derived by adding the total prevalence estimates for ankylosing spondylitis among whites, psoriatic arthritis, peripheral enteropathic arthritis, and the low estimate for axial enteropathic arthritis (130 + 101 + 65 + 50 = 346); undifferentiated spondylarthritis was excluded. The high range was derived by adding the total prevalence estimates for nationally representative ankylosing spondylitis, psoriatic arthritis, peripheral enteropathic arthritis, the high estimate for axial enteropathic arthritis, and undifferentiated spondylarthritis (520 + 101 + 65 + 250 + 374 = 1,310).

a number of diverse regions including New England; Manitoba, Canada; and 13 other centers across Canada. The prevalence of JCA from 2 Canadian studies was 3.2 and 4.0 per 100,000 children (40).

The prevalence of JRA in the US in different published reports ranged from 1.6 to 86.1 per 100,000. Data from the NHIS suggested a prevalence of 150 per 100,000 for all types of childhood arthritis, including JRA, juvenile spondylarthritis, Lyme disease, arthritis associated with the less common pediatric connective tissue diseases, and other types of childhood arthritis. The prevalence of JCA (the name for JRA outside the US) found in a population-based study in Australia, in which respondents were surveyed door to door (41), was far higher (400 per 100,000) than has been found in other studies.

In summary, there are very wide variations in the reported prevalences of chronic inflammatory arthritides of childhood, such as JRA and juvenile spondylarthritis. The lack of comparable prevalence estimates across different regions in the US makes it difficult to estimate the total number affected. Perhaps the best prevalence estimates come via a novel approach using data from pediatric ambulatory care visits recorded in the 2001–2004 National Ambulatory and Medical Care Survey and the NADW ICD-9-CM case definition for adults (6) modified to reflect pediatric conditions, by which it was estimated that 294,000 children ages 0–17 years (95% CI 188,000–400,000) were affected by the broadly defined "arthritis or other rheumatic conditions" (42).

Spondylarthritides. The spondylarthritides (more contemporary term for what is synonymously referred to in many earlier publications as "spondylarthropathies") are a family of diseases that includes ankylosing spondylitis (AS), reactive arthritis (formerly known as Reiter's syndrome), psoriatic arthritis, enteropathic arthritis (associated with ulcerative colitis or Crohn's disease), juvenile spondylarthritis, and undifferentiated spondylarthritis, which encompasses disorders expressing elements of but failing to fulfill criteria for the above diseases. The prevalence of AS and other spondylarthritides parallels the frequency of the genotype HLA–B27.

Ankylosing spondylitis. Among studies of white Europeans and East Asians, the reported prevalence of AS has varied between 30 per 100,000 and 900 per 100,000 (reflecting differences in HLA–B27 frequency and in patient referral and disease ascertainment) (43–45). In the US, a 1979 study from Rochester, Minnesota showed a prevalence of 129 per 100,000 in a Caucasian population (46). Prevalence data suggest that AS occurs less frequently in African Americans than in whites (47).

The overall prevalence of severe or moderate radiographic sacroiliitis on pelvic radiographs in men ages 25–74 years in the NHANES I was 730 per 100,000; among women ages 50–74 years, the prevalence was 300 per 100,000 (48) (Table 2). Of those with moderate to severe radiographic sacroiliitis, only 7.6% were currently experiencing "significant pain in their lower backs on most days for at least one month." Since questions

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