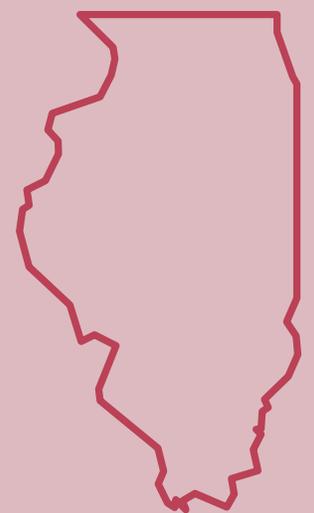


2002 ILLINOIS ARTHRITIS DATA REPORT

Approximately one in four
adults in Illinois reports arthritis or
chronic joint symptoms.



ILLINOIS
DEPARTMENT
OF PUBLIC
HEALTH

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FROM THE DIRECTOR

Dear Colleague:

The Illinois Department of Public Health (IDPH) is pleased to share with you a copy of the *Illinois Arthritis Data Report*. Arthritis affects the quality of life of the people who experience this painful condition, as well as their family members and caregivers. It is estimated that 2.41 million, or 26.4 percent of Illinois citizens live with some form of arthritis.

This report serves as an initial step in defining the burden of arthritis in Illinois. It represents an analysis of arthritis-related data gathered from the IDPH Behavioral Risk Factor Surveillance System (BRFSS) for the year 2000. The report will be utilized to increase awareness of arthritis as a public health issue and to provide direction for future program planning. Ultimately, it is our intent that this report also will serve as a tool to assist in achieving the mission of the Illinois Arthritis Partnership — to improve the quality of life for Illinoisans affected by arthritis.

The Department extends its appreciation to those who served on the planning committee and contributed their time and expertise to the development of this report.

Sincerely,



John R. Lumpkin, MD
Director of Public Health

EXECUTIVE SUMMARY

Arthritis and other rheumatic conditions currently affect almost 43 million Americans. By the year 2020, this number is expected to rise to 60 million Americans because of the maturing of the "baby boomers." The Illinois Arthritis Data Report 2002 documents the frequency and burden of arthritis in Illinois.

This report was initiated by the Illinois Department of Public Health as part of the Illinois Arthritis Initiative (IAI), a state planning program to reduce the burden of arthritis in Illinois. Current efforts focus on those persons affected by arthritis in Illinois (e.g., persons with arthritis, family members, friends, and health care providers), with an emphasis on minorities, rural populations and the under served. Program activities focus on the National Arthritis Action Plan (NAAP), Illinois Arthritis Action Plan (IAAP), and the Healthy People 2010 (HP2010) arthritis-related objectives and identified state priorities.

The initiative has chosen to define "arthritis" as encompassing more than 120 rheumatic diseases and conditions affecting joints, the surrounding tissues and other connective tissues. It may cause pain, stiffness and swelling not just in joints but other supporting structures of the body such as muscles, tendons, ligaments and bones. Some rheumatic diseases are also autoimmune disorders and affect other parts of the body, including internal organs.

This Illinois Arthritis Data Report describes:

- surveillance and data sources that are being used to address short-term arthritis issues;
- information that is available currently from cited data sources;
- gaps in the data sources; and
- possibilities for developing long-term data sources.

Prior to this report, arthritis frequency and disease burden in Illinois could only be inferred by applying national rates to the age, race and gender distributions of the Illinois population. This report represents the first time Illinois-specific data has been presented directly.

The primary data for this report come from the Behavioral Risk Factor Surveillance System (BRFSS) arthritis survey done in Illinois in 2000. Information obtained from the BRFSS represents the first known

systematic collection of statewide data on both arthritis and quality of life related to arthritis. These data are important to understanding the present state of arthritis in Illinois, for future program planning and to provide a baseline for future comparisons.

BRFSS results for 2000 show that arthritis affects 26 percent of adult Illinois residents. Of those, 8 percent felt some limitation in their activities because of joint symptoms, and 8.5 percent had been unable to do usual activities (e.g. self-care, work, recreation) during the preceding 30 days because of arthritis pain.

Other highlights of this report include the following:

- Certain segments of the adult population (e.g. older persons, women, and those in rural areas) of Illinois may be more impacted by rheumatic diseases.
- Persons with arthritis report poor quality of life in the form of more days when their physical and mental health are compromised.
- Persons with arthritis report noticeable pain as often as two days each week (on average) and curtailment of activities about 20 percent of the time.
- Persons with arthritis need to be directed to appropriate medical treatment.

An important goal of the Illinois Arthritis Initiative is to focus on existing and potential state data sources in an effort to develop a comprehensive arthritis surveillance system. Currently, the BRFSS provides data about prevalence rates within specific populations, describes arthritis awareness, enables the comparison of figures related to quality of life for those with arthritis and those without rheumatic diseases and provides measures of various health behaviors recognized as having the potential to prevent or hinder the progress of some forms of arthritis.

Members of the Illinois Arthritis Partnership and its Surveillance and Data Work Group (SDWG) plan to continue to rely on BRFSS to provide program data. For this to occur, arthritis-related questions must continue to be included on the BRFSS state and county questionnaires. Also, BRFSS needs to be expanded to allow for state and county data collection addressing other arthritis-related issues as well. One example

EXECUTIVE SUMMARY

[C O N T I N U E D]

would be the inclusion of questions that parallel the HP2010 arthritis-related objectives. This would enable state progress toward national objectives to be monitored.

Additional state data sources that will more effectively document the burden of arthritis in Illinois are being sought and will be used to evaluate progress toward Illinois Arthritis Action Plan program objectives.

Additional sources may include, but are not limited to--

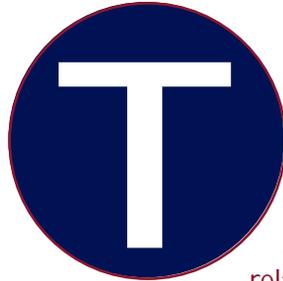
- outpatient ambulatory care data;
- managed care organizations data;
- BRFSS follow-back data;
- pharmacy data;
- Illinois hospital discharge data;
- Arthritis Foundation (two state chapters) data; and
- Illinois Arthritis Partnership survey data

The National Arthritis Data Work Group (NADW) provides estimates of the frequency and impact of arthritis and specific musculoskeletal conditions. Information obtained from the NADW serves both as a comparison and as a complement to that collected in Illinois by BRFSS.

The SDWG has developed a long-range plan for enhancing arthritis surveillance and data activities. Plans include continuing to support the data needs of work groups and pursuing the following comprehensive surveillance efforts:

- continue and expand current BRFSS surveillance efforts;
- monitor the quality of life of persons with arthritis;
- assess disparities in health care and access to care issues;
- increase the supply and geographic availability of self-management opportunities;
- assure that all Illinois residents are aware of resources for early diagnosis, treatment, management, prevention and support systems for arthritis;
- identify and utilize additional state data sources and enhance existing data collection procedures and tools; and
- evaluate the Illinois Arthritis Partnership for partner satisfaction and achievement of objectives.

INTRODUCTION



This is the first comprehensive report describing the burden of arthritis on the people of Illinois. In public health, burden is traditionally defined as prevalence, morbidity and mortality related to a health problem. Recently, a more popular definition has emerged that expands the public health meaning to include associated factors such as quality of life and activity limitations. This report will summarize some of these measures and others that describe the effects of arthritis on Illinois citizens.

INFORMATION FOR THE ILLINOIS ARTHRITIS DATA REPORT

The sources of information for this report are the Behavioral Risk Factor Surveillance System (BRFSS) for Illinois, coordinated through the Illinois Department of Public Health, Center for Health Statistics.

This report presents new data collected through the BRFSS in 2000 that can better describe the burden of arthritis for persons in the state of Illinois.

This survey data has enabled us to:

- provide prevalence rates within specific population groups;
- describe the extent to which persons are aware of their particular type of arthritis and the number of those under a physician's care;
- present comparative figures related to quality of life issues for those with arthritis; and
- document health behaviors, care needs and recognized preventive measures that might curtail or slow progression of arthritis.

WHAT IS ARTHRITIS?

Arthritis encompasses more than 120 rheumatic diseases and conditions affecting joints, the surrounding tissues and other connective tissues. It may cause pain, stiffness and swelling not just in joints but other supporting structures of the body such as muscles, tendons, ligaments and bones. Some rheumatic diseases are also autoimmune disorders and affect other parts of the body, including internal organs.

Examples of rheumatic diseases include the following: osteoarthritis, rheumatoid arthritis, fibromyalgia, systemic lupus erythematosus, juvenile rheumatoid arthritis and gout. These six diseases provide the focus for the Illinois Arthritis Action Plan.

- **OSTEOARTHRITIS** is the most common type of arthritis and affects an estimated 20.7 million adults in this country. It primarily impacts cartilage (the tissue that cushions the ends of bones within joints) and can lead to pain, limited motion, deformity and loss of function of the joint. In its most severe form, untreated osteoarthritis can result in severe joint damage and disability.
- **RHEUMATOID ARTHRITIS** is an inflammatory disease of the synovium (lining of the joint) that results in pain, stiffness, swelling, deformity and loss of function of the joint. In the most severe form, rheumatoid arthritis can cause joint symptoms plus fatigue, fever and a general sense of illness for many years, resulting in severe joint damage and disability. Less common than osteoarthritis, it affects 2.1 million persons in the United States.
- **FIBROMYALGIA** is a chronic disorder that causes pain and stiffness throughout the tissues that support and move the bones and joints. Pain and localized tender points occur in the muscles and tendons, especially those of the neck, spine, shoulders and hips. Other common symptoms are widespread pain, fatigue and sleep disturbance. Fibromyalgia affects approximately 5 million people in the United States.

- **LUPUS** can be classified as one of four types: discoid lupus erythematosus, drug-induced systemic lupus erythematosus, neonatal lupus and systemic lupus erythematosus (SLE). SLE is a chronic, inflammatory, multisystem disorder of the immune system. Because it is the most common type of lupus (more than 70 percent of all diagnosed lupus is SLE), the Illinois Arthritis Action Plan will focus on SLE. According to the American College of Rheumatology, the prevalence of SLE is 40-50 cases per 100,000 population.
- **GOUT** is a type of arthritis that causes sudden, severe attacks of pain, swelling, redness, warmth and tenderness in the joints. It results from deposits of needle-like crystals of uric acid, a byproduct of the breakdown of purines or waste products in the body, in connective tissue, joint spaces or both. These deposits lead to swelling, redness, heat, pain and stiffness in the joints. It usually affects the joint of the big toe but can occur in feet, ankles, knees, hands and wrists.

Gout accounts for about 5 percent of all cases of arthritis. According to the American College of Rheumatology, the prevalence rate for gout in all Americans is 840 cases per 100,000 population.

- **JUVENILE RHEUMATOID ARTHRITIS (JRA)** is arthritis that causes joint inflammation and stiffness for more than six weeks in a child 16 years of age or younger. Children can develop almost all types of arthritis that affect adults, but JRA is the most common type of arthritis in young children. Nearly 300,000 children have arthritis with about 70,000 to 100,000 of these children having juvenile rheumatoid arthritis.

BURDEN OF ARTHRITIS

NATIONALLY

Arthritis and other rheumatic conditions affect almost 43 million Americans. By the year 2020, this number is expected to rise to 60 million. Of much greater concern is the fact that arthritis and related conditions are the leading causes of disability for people in this country. Direct and indirect costs to society from arthritis are conservatively estimated to exceed \$65 billion each year.

IN ILLINOIS

In 2000, arthritis-related and quality of life questions were included on the Illinois BRFSS survey. These questions were added to the survey, which is conducted among Illinois adults (persons 18 years of age and older), in order to estimate the prevalence of arthritis in the state. To generate an estimate of statewide prevalence of arthritis and chronic joint symptoms, responses to the following three BRFSS arthritis-related questions were used:

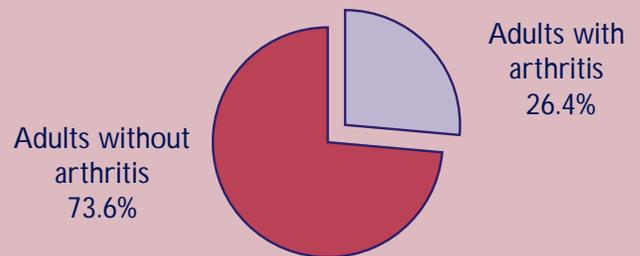
1. During the past 12 months, have you had pain, aching, stiffness, or swelling in or around a joint?
2. Were these symptoms present on most days for at least one month?
3. Have you ever been told by a doctor that you have arthritis?

For the purposes of this report, arthritis is defined as chronic joint symptoms and/or arthritis diagnosis. Therefore, the estimates were based on those responding "yes" to questions 1 and 2, and/or those who answered "yes" to question 3.

From responses to these three BRFSS questions, **Figure 1** shows that an estimated 26.4 percent of the adults in Illinois (approximately 2.4 million people) suffer from arthritis or chronic joint symptoms.

Figure 1:

An estimated 2,411,000 Adults in Illinois Have Arthritis or Chronic Joint Symptoms

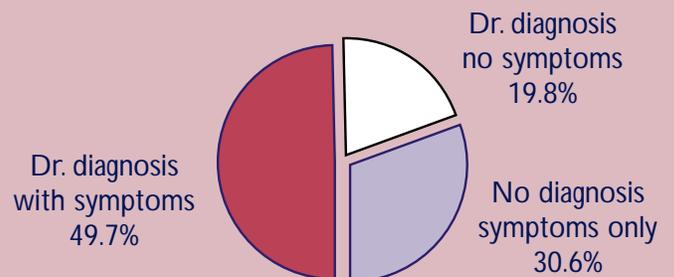


Source: 2000 Illinois Behavioral Risk Factor Surveillance System

Figure 2 shows how the 26.4% (in Figure 1) are characterized by diagnosis and symptoms.

Figure 2:

Persons in Illinois With Arthritis and/or Chronic Joint Symptoms



Source: 2000 Illinois Behavioral Risk Factor Surveillance System

ILLINOIS BRFSS

DATA BREAKDOWNS

Additional breakdown of Illinois BRFSS data yielded age, gender, education level, income level, urbanicity, extent of arthritis awareness and various quality of life factors. Following are these BRFSS data.

A. WHO HAS ARTHRITIS?

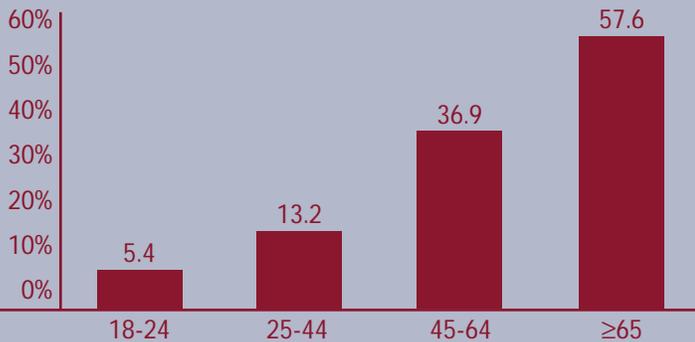
Although it is known that arthritis affects all ages, both genders and all race and ethnic groups, some groups are more likely to be affected than others.

Age

Arthritis affects all ages, including a significant number of people in the prime of their life. However, as **Figure 3** shows, older persons are more commonly affected by arthritis. The prevalence rates for arthritis and chronic joint disease rises from 5.4 percent for persons 18-24 years old to 57.6 percent for those 65 years and older.

Figure 3:

ILLINOIS ADULTS WITH ARTHRITIS BY AGE GROUP



Source: 2000 Illinois Behavioral Risk Factor Surveillance System

Race

Currently, no accurate race data is available. The SDWG is identifying means to collect state race data.

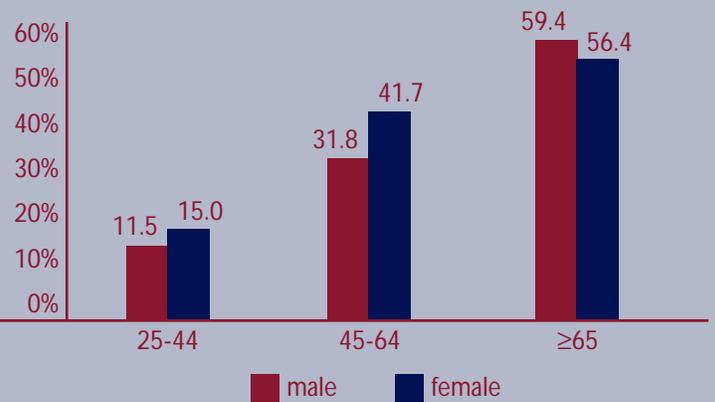
Gender

Arthritis is the most prevalent chronic condition in women (NIAMS Report, 1997).

When broken down by age, **Figure 4** demonstrates that the prevalence rate is usually higher in women. In the 65 and over age group, the prevalence among the groups becomes more equal.

Figure 4:

ARTHRITIS BY AGE AND GENDER GROUPS



Source: 2000 Illinois Behavioral Risk Factor Surveillance System

ILLINOIS BRFSS

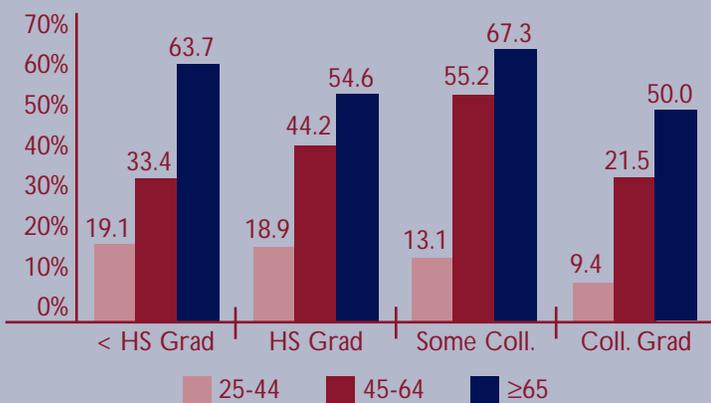
DATA BREAKDOWNS

Education

In terms of educational level, **Figure 5** shows the lowest prevalence rate for arthritis is among college graduates age 25-44 (9.4 percent). This could be related to the age distribution within these four education groups. Older persons may have fewer years of formal education compared to younger persons; older persons are more likely to have arthritis than younger persons.

Figure 5:

ARTHRITIS BY EDUCATION LEVEL AND AGE GROUP



Source: 2000 Illinois Behavioral Risk Factor Surveillance System

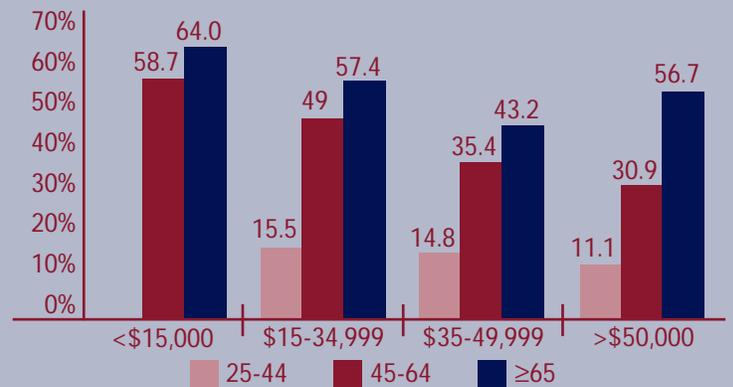
Income

Figure 6 shows that persons in the two lowest household income groups report higher prevalence rates for arthritis. However, again, these results could be related to the age distribution within the income groups. Older persons on fixed incomes might have lower household incomes; older persons are more likely to have arthritis.

Note: The age group 25-44 in the "under \$15,000" income category was not included because of small sample size.

Figure 6:

ARTHRITIS BY AGE GROUP AND HOUSEHOLD INCOME

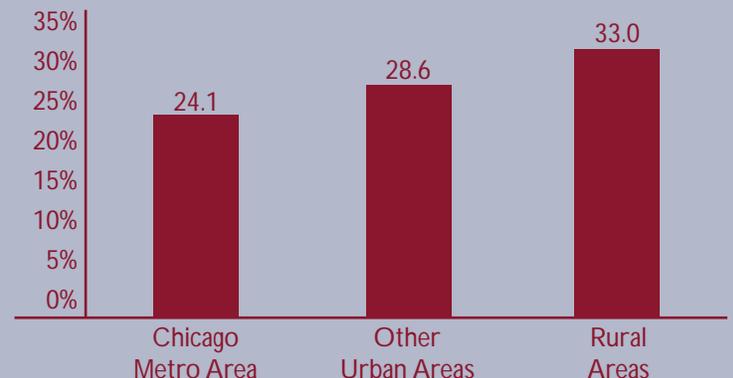


Urbanicity

Figure 7 represents how the BRFSS in Illinois divides the state into strata related to population density. Persons living in rural counties (83 of the 102 Illinois counties) have a higher prevalence rate (33 percent) of arthritis than those living elsewhere in Illinois. The Chicago metropolitan area has the lowest arthritis prevalence of the three strata at 24.1 percent.

Figure 7:

ARTHRITIS BY URBANICITY STRATA



Source: 2000 Illinois Behavioral Risk Factor Surveillance System

ILLINOIS BRFSS

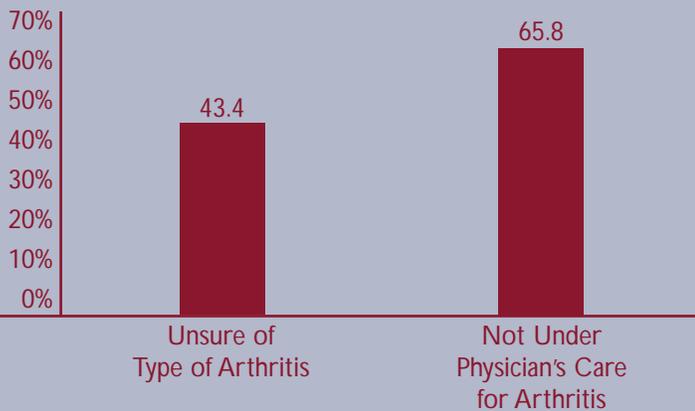
DATA BREAKDOWNS

B. ARTHRITIS AWARENESS

In **Figure 8**, of persons with arthritis in Illinois, slightly less than one-half (43.4 percent) did not know or were unsure of the type of arthritis they had. More significantly, almost two-thirds (65.8 percent) were not under a physician's care for arthritis. These people may be suffering unnecessarily.

Figure 8:

ARTHRITIS AWARENESS



Source: 2000 Illinois Behavioral Risk Factor Surveillance System

C. QUALITY OF LIFE

Arthritis is a chronic disease that leaves many people feeling that they have been sentenced to a lifetime of disability and a limited quality of life.

Persons with arthritis report far more days when their physical and mental health are not good compared to persons without arthritis. In addition, those with arthritis report many more days each month when their health keeps them from doing their usual activities compared to those without arthritis. For these analysis, the different age distributions of the group of persons with arthritis and those without were taken into consideration.

MEAN NUMBER OF DAYS HEALTH AFFECTED IN A MONTH

DAYS PHYSICAL HEALTH NOT GOOD

With arthritis or chronic joint symptoms	6.4
Without arthritis or chronic joint symptoms	1.8

DAYS MENTAL HEALTH NOT GOOD

With arthritis or chronic joint symptoms	3.1
Without arthritis or chronic joint symptoms	2.4

DAYS HEALTH KEPT FROM DOING USUAL ACTIVITIES

With arthritis or chronic joint symptoms	5.6
Without arthritis or chronic joint symptoms	1.9

MEAN NUMBER OF DAYS PER MONTH WITH ARTHRITIS PAIN

Adults with arthritis or chronic joint symptoms	8.5
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PERCENTAGE OF ADULTS

With arthritis or chronic joint symptoms with activity limitations due to arthritis	37.4
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ILLINOIS BRFSS

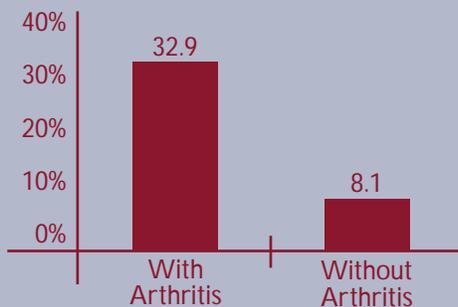
DATA BREAKDOWNS

Questions related specifically to arthritis were asked only of those who self-reported arthritis according to the definitions used in this report. Persons with arthritis report an average of 8.5 days each month during which they experience pain. More than one-third (37.4 percent) of those who met the definition for arthritis reported that the disease limits their activities.

As **Figures 9 and 10** show, a higher proportion of persons with arthritis report needing help with both routine and personal care compared to those without arthritis. These results considered the differences in age when comparing persons with and without arthritis.

Figure 9:

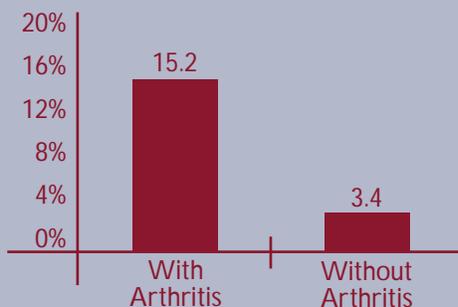
NEED HELP WITH ROUTINE CARE



Source: 2000 Illinois Behavioral Risk Factor Surveillance System

Figure 10:

NEED HELP WITH PERSONAL CARE



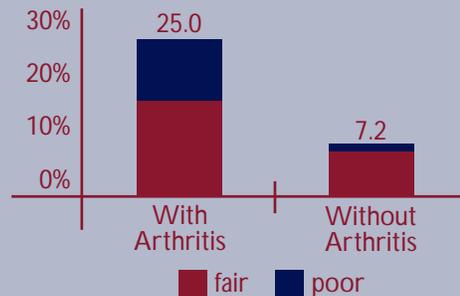
Source: 2000 Illinois Behavioral Risk Factor Surveillance System

D. HEALTH AND HEALTH BEHAVIORS

In general, **Figure 11** demonstrates approximately one of four persons with arthritis perceived his/her health to be only "fair" or "poor" when compared to persons without arthritis. This difference takes into account that the majority of people with arthritis are generally older and, therefore, may be subject to other chronic conditions in addition to arthritis.

Figure 11:

PERCEIVED HEALTH STATUS Fair or Poor



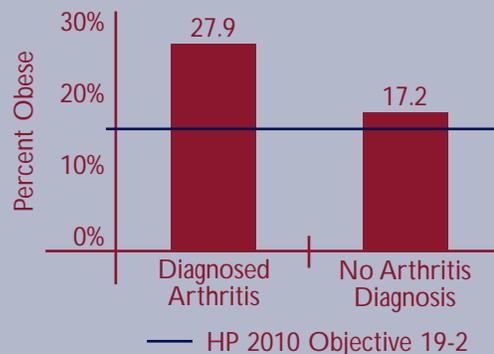
Source: 2000 Illinois Behavioral Risk Factor Surveillance System

E. OBESITY

BRFSS data are compared to the HP2010 obesity-related objective 19-2, "Reduce the proportion of adults who are obese," in **Figure 12**. Among persons with arthritis, there is higher prevalence (27.9 percent) of obesity compared to those without arthritis (17.2 percent).

Figure 12:

ILLINOIS ADULT OBESITY STATUS BY ARTHRITIS DIAGNOSIS



Source: 2000 Illinois Behavioral Risk Factor Surveillance System

CONCLUSIONS

A

Arthritis is an important public health problem in Illinois. This data report describes important segments of Illinois' adult population who may be disproportionately affected by rheumatic diseases. Analysis of state BRFSS data indicates that older persons, women and those in rural areas have higher prevalence rates for arthritis than comparison groups. These people need to be directed to appropriate medical treatment.

Persons with arthritis are more likely to report poor quality of life in the form of more days when their physical and mental health are compromised. They report noticeable pain as often as two days each week (on average) and curtailment of usual activities about 2 percent of the time. Just understanding those statistics helps to bring home the impact arthritis has on individuals.

THE FUTURE

The SDWG has developed a long-range plan for enhancing arthritis surveillance and data activities. It includes continued support for the Illinois Arthritis Action Plan and its data needs for the following comprehensive surveillance efforts —

- continue and expand current BRFSS surveillance efforts;
- monitor the quality of life of persons with arthritis;
- assess disparities in health care and access to care issues;
- assure that all Illinois residents are aware of resources for early diagnosis, treatment, management, prevention and support systems for arthritis;
- identify and utilize additional state data sources and enhance existing data collection procedures and tools; and
- evaluate the Illinois Arthritis Partnership for partner satisfaction and achievement of objectives.

An important goal of the IAI is to focus on existing and potential state data sources in an effort to develop a comprehensive arthritis surveillance system. Currently, the BRFSS provides data about prevalence rates within specific populations, describes arthritis awareness, enables the comparison of figures related to quality of life for those with arthritis and those without rheumatic diseases and provides measures of various health behaviors recognized as having the potential to prevent or hinder the progress of some forms of arthritis.

Members of the Illinois Arthritis Partnership and its SDWG will continue to rely on BRFSS to provide program data. For this to occur, arthritis-related questions must continue to be included on the BRFSS state and county questionnaires. Also, the BRFSS survey needs to be expanded to allow for state and county data collection addressing other arthritis-related issues as well. One example would be the inclusion of questions that parallel the HP2010 arthritis-related objectives. This would enable state progress toward national objectives to be monitored.

Additional state data sources that will more effectively document the burden of arthritis in Illinois are being sought and will be used to evaluate progress toward IAAP program objectives. Additional sources may include, but are not limited to —

- outpatient ambulatory care data,
- managed care organization data,
- BRFSS follow-back data,
- pharmacy data,
- Illinois hospital discharge data,
- Arthritis Foundation (two state chapters) data, and
- Illinois Arthritis Partnership survey data.

In addition, the NADWG provides estimates of the frequency and impact of arthritis and specific musculoskeletal conditions. Information obtained from the NADW serves both as a comparison and as a complement to that collected in Illinois by the BRFSS.

ABOUT THE PARTNERSHIP

The Illinois Arthritis Partnership consists of approximately 70 members representing more than 55 agencies and organizations. The partnership's multidisciplinary perspective contributes greatly to the task of reducing the burden of rheumatic diseases and conditions in Illinois. Four work groups address specific arthritis-related issues including surveillance and data, public education, professional education, and public policy and infrastructure.

Partnership objectives include the following:

- Development of a comprehensive statewide focus for arthritis, utilizing existing programs and private and public networks; and
- Creation of a long-range, comprehensive and integrative plan of action (*Illinois Arthritis Action Plan*).

For further information about the state's arthritis initiative or to become a member of the partnership, contact the **Illinois Department of Public Health at 217-782-3300**.

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