Prevalence and Impact of Chronic Joint Symptoms—Seven States, 1996

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ARTHITIS AND other rheumatic conditions are the leading cause of disability in the United States, affecting 42.7 million persons and costing $65 billion in 1992. These numbers will increase by 2020 as the population ages. Few surveys exist to directly determine the prevalence and impact of arthritis at the state level. To address this gap, in 1995 state health departments and CDC developed a standardized, optional arthritis module for the Behavioral Risk Factor Surveillance System (BRFSS). This report summarizes the results of the analyses of 1996 data in seven states. The findings indicate that the prevalence and impact of “chronic joint symptoms”—a proposed indicator for true arthritis and other rheumatic conditions—is high and variable among states and that a large proportion of persons with arthritis diagnosed by a doctor do not know the type of arthritis they have.

The BRFSS is an ongoing, state-based, random-digit-dialed telephone survey that collects self-reported health information from a representative sample of the civilian, noninstitutionalized U.S. population aged ≥18 years. In 1996, a total of 15,656 persons in Arizona (n = 1957), Montana (n = 1803), New Jersey (n = 2894), Pennsylvania (n = 3595), and Rhode Island (n = 1849) responded to the arthritis module. Persons who had chronic joint symptoms were defined as those answering “yes” to two questions: “During the past 12 months, have you had pain, aching, stiffness or swelling in or around a joint?” and “Were these symptoms present on most days for at least one month?” Persons who had chronic joint symptoms were considered to have arthritis diagnosed by a doctor if they answered “yes” to “Have you ever been told by a doctor that you have arthritis?” Persons who had arthritis diagnosed by a doctor were considered to know their type of arthritis if they specified a type in response to the question “What type of arthritis did the doctor say you have?” and were considered to have current doctor-based treatment for arthritis if they answered “yes” to “Are you currently being treated by a doctor for arthritis?” Weighted prevalence was used to estimate the number of persons with chronic joint symptoms in each state. Data were analyzed using SUDAAN®, and the results were weighted to account for the complex sample survey design.

The prevalence of chronic joint symptoms ranged from 12.3% (using the weighted prevalence, an estimated 7,422,000 persons) in New Jersey to 22.7% (901,000 persons) in Missouri. Population prevalences of self-reported activity limitation attributable to chronic joint symptoms in the seven states, 55.7%-65.6%, were limited in activity. Among persons who had chronic joint symptoms in the seven states, 55.7%-65.6% had arthritis diagnosed by a doctor. Among persons with arthritis diagnosed by a doctor, 30.5%-53.3% did not know their type of arthritis, and 43.0%-52.5% were being treated by a doctor for their arthritis.

Within-state analyses indicated similar distributions of demographic and other variables. For example, in Pennsylvania, the prevalence of chronic joint symptoms increased markedly with age and was higher among women than men. After adjustment for age and sex, prevalence was higher among non-Hispanic whites; among persons with fair or poor health status; and among persons who were overweight and physically inactive. The findings for persons who had activity limitation attributable to chronic joint symptoms showed similar patterns.

CDC Editorial Note: The findings in this report indicate that the prevalence of and activity limitation attributable to chronic joint symptoms are high and variable among the seven states. The approximately 40% of persons with chronic joint symptoms who had not been told by a doctor that they had arthritis presumably consists of the large proportion of persons who had not seen a doctor for a diagnosis, persons who had other chronic rheumatic conditions that were not classified clinically as arthritis (e.g., persons who had bursitis), and persons who used nontraditional medical practitioners that they would not classify as doctors. Because many persons with arthritis diagnosed by a doctor did not know their type of arthritis, they may be poorly educated about their disease and missing the documented benefits of self-management (e.g., an approximately 20% reduction in pain and a 40% reduction in the number of doctor visits). The proportion of respondents with arthritis diagnosed by a doctor who were currently being treated by a doctor was low given the chronicity of arthritis and the benefits of doctor-based treatment (e.g., medications, physical therapy, and joint replacement surgery). The findings for Pennsylvania indicate much higher rates of chronic joint symptoms among persons with a fair or poor health status and risk behaviors of overweight and physical inactivity, suggesting that these persons are at higher risk for additional adverse health outcomes (e.g., heart disease and diabetes).

The results presented in this report are subject to at least three limitations. First, BRFSS does not survey persons without telephones, persons in the military or institutions, or persons aged 18 years. Therefore, the numbers may underestimate the prevalence of chronic joint symptoms. Second, the validity of self-reported chronic joint symptoms is
not known. The National Arthritis Data Workgroup has proposed that for self-reported data such as the BRFSS and the redesigned 1996 National Health Interview Survey (NHIS), chronic joint symptoms serve as a new indicator for a true diagnosis of arthritis and other rheumatic conditions. The patterns of chronic joint symptoms by demographic characteristics parallel those seen in analyses of a previous indicator of arthritis and other rheumatic conditions using earlier NHIS data,7 suggesting the usefulness of the new indicator. Finally, observed state-specific differences may reflect uncontrolled differences in population composition (e.g., age, sex, and race), socioeconomic status, or occupational and other characteristics.

Additional analyses of these data are planned to examine the relations between chronic joint symptoms, arthritis diagnosed by a doctor, and activity limitations and other BRFSS measures (e.g., health-related quality of life and health promotion/disease prevention behaviors). A public health response to this large and increasing problem requires action at the state level8 to raise public awareness of the impact of chronic joint symptoms on the personal and public health opportunities to reduce the consequences.9 The arthritis BRFSS module can be used to gather state-level data directly about persons with chronic joint symptoms. States need direct measures of arthritis prevalence and impact rather than indirect estimates that may not account for variation from potentially confounding demographic, occupational, or other characteristics. Direct state-specific measures can help focus appropriate interventions10 to help meet proposed national health objectives for arthritis for 2010.

State health agencies, arthritis organizations, and other interested groups are drafting the National Arthritis Action Plan—A Public Health Strategy under the sponsorship of CDC and the Arthritis Foundation. This publication, planned for release later this year, is intended to provide a comprehensive public health strategy for state health departments, the 60 Arthritis Foundation chapters, and others in the public health community to reduce the arthritis burden in the United States.

Strategies for Providing Follow-up and Treatment Services in the National Breast and Cervical Cancer Early Detection Program—United States, 1997

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THE BREAST and Cervical Cancer Mortality Prevention Act of 1990 authorized CDC to establish the National Breast and Cervical Cancer Early Detection Program (NBCCEDP) to increase screening services for women at low income levels who are uninsured or underinsured.1 Although the NBCCEDP covers most diagnostic services that women need after receiving an abnormal mammography or Papnicolaou (Pap) test result, the program does not reimburse for breast biopsies. In addition, the Act prohibits the use of NBCCEDP funds for cancer treatment. Participating health agencies must ensure that NBCCEDP clients receive timely, appropriate diagnostic and treatment services. In 1996, CDC began a case study to determine how early detection programs in seven participating states (California, Michigan, Minnesota, New Mexico, New York, North Carolina, and Texas) identified resources and obtained diagnostic and treatment services. This report summarizes the results of the study,7 which indicated that respondents in these states reported that treatment had been initiated for almost all NBCCEDP clients in whom cancer was diagnosed. However, respondents also considered the strategies used to obtain these services as short-term solutions that were labor-intensive and diverted resources away from screening activities.

In the seven states, NBCCEDP-sponsored screening services had been provided for ≥3 years, and breast cancer had been diagnosed in ≥60 women. The states were selected to provide a range of geographic locations, a combination of urban and rural populations, and racial/ethnic diversity among program clients. Researchers conducted semi-structured interviews with 192 persons affiliated with the seven state programs. Of these interviewees, 120 (63%) were providers of screening, diagnostic, and/or treatment services; 58 (30%) were state program staff; and 14 (7%) were coalition members. Interviews included topics such as guidelines related to diagnostic and treatment services, strategies used to obtain and pay for services, level of effort required to secure these services, and changes in strategies over time. Each interview was tape recorded and transcribed. Using a systematic scheme derived from the research questions, three researchers coded the same transcripts until an inter-rater agreement of 80% was reached. Thereafter, all transcripts were coded independently. Coding results were entered into text analysis software that sorts text from transcripts into sets of information, themes, and evidence relevant to the specific research questions.3 The results reflect a synthesis of the interviewees’ responses.

Respondents described several strategies used to ensure necessary diagnostic and treatment services for women screened through the NBCCEDP. State-level strategies in all states included (1) computerized tracking and follow-up systems that used program surveillance data to identify and manage clients in need of diagnostic and treatment services; (2) provisions in contracts requiring screening providers to arrange for diagnostic follow-up and treatment before screening women; and (3) arrangements with provider groups and state professional associations for free or reduced-cost services for NBCCEDP clients. All states also had access to public or private funds to help support services not covered by the program; such revenue sources included state appropriations from general or tobacco tax revenues or funds from private founda-

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tions. These funds were available primarily for breast diagnostic services.

Local strategies tailored to the needs of individual clients were used to obtain diagnostic and treatment services. Common strategies reported by respondents included the following: providers billed public or private insurance plans; providers or local health departments helped clients apply for public assistance programs; providers referred clients to public hospitals; county indigent-care funds and hospital community-benefit programs financed services; clients received services through individually negotiated payment plans; and clients paid reduced or full fees for services.

Respondents strongly supported the continued growth of NBCCEDP and its goals but expressed several concerns. First, considerable time and effort were involved in developing and maintaining systems for diagnostic follow-up and treatment. Second, the process of identifying available resources within states for diagnostic and treatment services was considered labor-intensive. Third, the lack of coverage for diagnostic and treatment services negatively affected recruitment of providers and restricted the number of women screened. Fourth, respondents believed that an increasing number of physicians will not have the autonomy, because of changes in the health-care system, to offer free or reduced-fee services to NBCCEDP clients.

Respondents reported that arrangements for treatment were made for almost all NBCCEDP clients who received a diagnosis of breast cancer or invasive cervical cancer. Respondents stated that some women experienced time delays between screening, definitive diagnosis, and initiation of treatment. State program officials reported that, according to 1992-1996 surveillance data, small numbers of clients in whom cancer was diagnosed (i.e., from three to 13 women in each state) subsequently refused treatment. Because these clients were not interviewed, it could not be determined whether financial barriers contributed to their decisions to refuse treatment or their loss to follow-up.

Respondents were concerned that the NBCCEDP did not provide funding for all diagnostic procedures and treatment for the diseases for which clients were being screened; approaches for delivering services were fragmented; and the process of obtaining resources required substantial effort at the state, local, and provider levels. Respondents reported that the continuation of every strategy for diagnostic and treatment services beyond the next few years is uncertain.

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CDC Editorial Note: During July 1991-March 1997, the NBCCEDP provided 576,408 mammograms to women aged ≥40 years, and 3409 cases of breast cancer were diagnosed. During this same period, the program provided 732,754 Pap tests; 23,782 cases of cervical intraepithelial neoplasia and 303 cases of invasive cervical cancer were diagnosed. These totals included women referred to the program for diagnostic evaluation of an abnormal screening result. The NBCCEDP internal estimates suggested that during this period only 12%-15% of uninsured women aged 40-64 years in the United States had been screened by the program (CDC, unpublished data, 1997).

Screening alone does not prevent cancer deaths; it must be coupled with timely and appropriate diagnostic and treatment services. The Congressional mandate for NBCCEDP requires grantees to take all appropriate measures to ensure provision of services required by women who have abnormal screening results. CDC provides funds for case management to help these women access health-care services. To increase the comprehensive nature of the program, CDC recently approved the use of NBCCEDP funds for breast biopsies.

The results of this study indicate that state health departments and their partners in the seven states had developed a wide range of strategies for diagnostic and treatment services in the absence of program resources. However, the time and effort required to arrange and maintain these services diverted resources away from screening activities.

This study was subject to at least two limitations. First, the results were based solely on the experience and opinions of informed professionals affiliated with the program and did not include the perspectives of NBCCEDP clients. Second, the results may not reflect the program experiences in other states. Case-study methods, however, are an appropriate and well-accepted approach to gaining in-depth understanding of complex programs in real-life situations. The validity of the findings was enhanced by developing standard instruments to guide the semi-structured interviews, protecting the confidentiality of respondents’ remarks, using interview transcripts for data analysis rather than relying on interviewer notes, and obtaining feedback concerning state summary reports from respondents.

As more women are screened by the NBCCEDP, a greater burden will be placed on participating health agencies, providers, and other partners to obtain resources for breast and cervical cancer treatment. Case-management services will continue to be essential in helping underserved women overcome financial, logistical, and other barriers to receiving these services. Other long-term solutions to ensure that women in the program receive necessary treatment services are being pursued.

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