

THE IMPACT OF CHRONIC DISEASE

A Sociomedical Profile of Rheumatoid Arthritis

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A large number of individuals with rheumatoid arthritis have been studied in order to better delineate the sociomedical problems experienced by patients with this chronic disease. Two hundred forty-five respondents were surveyed by use of a detailed questionnaire and interview, and the results indicate that major losses in the areas of work, finances, and family structure are extremely common. The majority of workers were totally disabled as a result of their disease. On the average, subjects in the group were earning only 50% of the income predicted for them had they not had arthritis. Sixty-three percent experienced a major change in their psychosocial status as a result of their disease. Work disability appears to be the most important sociomedical impact of rheumatoid arthritis since it is associated with significantly greater income and psychosocial losses. This evidence of numerous and serious sociomedical problems in persons with rheumatoid arthritis raises

questions of emphasis and approach for physicians involved in the clinical care of chronic rheumatic disease patients.

The prevalence of chronic disease in the industrialized nations is steadily increasing. At the present time, at least 30 million adults in the United States suffer from one or more chronic conditions that limit their activity (1,2), and this number will probably grow steadily as the mean age of the population increases in the decades to come. In light of this epidemiologic trend, it is almost certain that physicians will be caring ever more frequently for patients with chronic diseases. Medical education, however, tends to focus on the treatment of acute episodes. The development of effective communication and counseling skills, which are particularly important in the care of chronic disease patients, is seldom stressed. Thus, most physicians may not have the knowledge or skills required to deal effectively with such individuals (3,4).

A thorough understanding of the biology of a disease and its medical treatment is certainly essential to successful therapy. However, barring significant basic research breakthroughs, we are probably at a point of diminishing returns in the treatment of most chronic diseases, since we have reached the stage where additional medical or surgical therapy is apt to produce progressively smaller improvements in individual health status (5). Since chronic diseases also produce significant economic, social, and psychologic problems as a result of their biologic effects (6), it seems reasonable to turn our attention to these problems as we seek ways to improve the overall well-being of patients with these conditions.

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As a first step, we must better delineate the nature and extent of the sociomedical impacts of chronic disease on patients and their families. The clinical manifestations of a given disease have traditionally been clarified by means of a detailed description of a group of individuals with that condition. The sociomedical manifestations of a disease should lend themselves to clarification by a similar approach. Thus, the present study was designed to develop a detailed sociomedical profile of a specific chronic disease by means of an in-depth analysis of a large group of people with that illness. The disease in question is rheumatoid arthritis. This is an appropriate condition to study for a number of reasons. First, it is a chronic illness which, once established, usually lasts for the balance of a lifetime. Second, this illness generally produces significant sociomedical effects as a result of progressive physical impairment (7,8). Third, it exemplifies the epidemiologic trend in chronic disease. Since its prevalence rate increases with age (9), rheumatoid arthritis will become more common as the proportion of elderly individuals in the population grows.

METHODS

Twenty-five rheumatologists from 19 practice settings in the San Francisco and Boston metropolitan areas maintained prospective logs on all persons with rheumatoid arthritis (RA) seen during a 1-month period. The practice settings included 10 solo fee-for-service practices, 10 group fee-for-service practices, 4 public hospital clinics, 2 veterans administration hospital clinics, 2 university outpatient facilities, and a large health maintenance organization. The sampling procedure was designed to yield a survey population that included persons with a range of disease severities and socioeconomic backgrounds. It did not necessarily provide a random distribution of these characteristics.

Participating rheumatologists initially requested the cooperation of appropriate patients from their practices, then provided the study team with the names and addresses of potential participants. Physicians were instructed to consider only patients between the ages of 21 and 65 and to exclude those with other diseases. This sampling strategy was designed to exclude subjects with a high probability of having sociomedical problems due to aging or other diseases.

Subjects were administered an extensive structured survey over the telephone by trained interviewers. The survey elicited information on demographic characteristics, disease and treatment history, work and income effects, and psychosocial changes. The disease-related information included age of onset, duration, therapeutic history, functional capabilities (American Rheumatism Association functional class), and the degree of radiographic involvement (ARA anatomic stage) (10), which was obtained from each respondent's physician.

The sociodemographic items included age, sex, race, marital status, and education. The work-related items included occupation and estimates of physical demands and au-

tonomy in the workplace. Occupations were coded according to the three-digit classification of the Department of Labor's *Dictionary of Occupational Titles* (11) and then condensed into a four-way classification for analysis. The physical requirements of the premorbid occupation were ascribed by matching the three-digit code with data on physical characteristics published in conjunction with the *Dictionary* (12). Other items measured autonomy within work by assessing the extent to which respondents controlled the pace and activities of their jobs (13).

It has previously been demonstrated that the income losses produced by rheumatoid arthritis are a much greater financial burden for the average patient than are the costs of medical care. Economic impact was thus measured primarily in terms of lost earnings. Information of pre- and post-morbid individual earnings and family income sources was collected from all respondents. Income losses caused by rheumatoid arthritis were estimated by comparing the expected study-year wages of each respondent who was working at the time of disease onset to his or her actual earnings during the study year. Expected earnings for each individual were estimated by the following method: premorbid earnings were divided by the median earnings for that year of all U.S. workers of similar sex and occupation, and this ratio was applied to the 1976 earnings of that group to obtain an estimate of expected individual earnings. Individual income before disease was therefore considered to increase during the intervening years at the same rate as the median income of all full-time U.S. workers of similar sex and occupation. No adjustments were made for promotion and seniority on the one hand or for unemployment rates on the other. Income losses were then computed by subtracting expected from actual earnings. Individuals whose earned income was at least \$200 less than expected were classified as having income losses (14).

To estimate the prevalence of psychosocial impacts, information was gathered on the frequency of 5 specific changes: work disability, divorce, changes in family employment (increases to provide income or decreases to provide home care), change in residence, and changes in leisure activities. Response rates for all questionnaire items averaged 95%, with a minimum response of 85%. The data were analyzed by group mean comparisons, contingency tables, and Pearson correlation coefficients to explore the interaction of various factors. Appropriate statistical tests were used to evaluate the results of these analyses (Student's *t*-test, chi-square tests, *F*-test), using a significance level of $P < 0.05$ in each case.

RESULTS

Demographic profile. Two-hundred forty-five individuals with rheumatoid arthritis completed the detailed interview, 186 in San Francisco and 59 in Boston. There were 82 men (33%) and 163 women (67%) in the sample, and the average age of the group was 52 years. Eighty-four percent were white, 7% black, 7% Spanish, and 2% Oriental. Sixty-two percent were married, 16% were divorced or separated, 13% were widowed, and 9% had never married. The respondents and their spouses (when applicable) each averaged 12 years of education;

11% of the respondents were college graduates. There were no significant demographic differences between the east and west coast groups save for a higher percentage of Spanish and Oriental subjects in the west.

Disease profile. Rheumatoid arthritis began at an average age of 42 years in this group of subjects, and the vast majority of cases were diagnosed within 1 year. By the time of the study, the disease had been present for an average of slightly over 9 years. Seven percent of the sample were self-classified as fully functional (American Rheumatism Association class I), 63% were able to conduct normal activities despite discomfort or joint limitation (ARA class II), 28% were significantly *limited in their usual activities or occupation* (class III), and 2% were largely or wholly incapacitated (class IV). As reported by their physicians, 16% had radiographic evidence of stage I disease, 28% showed stage II disease, 46% stage III, and 9% stage IV. Stage was highly correlated with duration ($r = 0.37$, $P < 0.00$), but functional class was not ($r = 0.07$, $P = 0.15$).

In keeping with the sampling approach, all patients had seen a rheumatologist about their arthritis. Seventy-five percent had also seen a general internist, 55% had consulted an orthopedic surgeon, and 50% had received care for their arthritis from a general practitioner. Twenty percent had been seen on at least one occasion by all four types of practitioners, and this situation was significantly more common in those with more severe disease as measured by either duration or anatomic stage. Sixty-two percent of the respondents had been sent to a physical therapist, 19% to an occupational therapist, and 15% had seen a social worker. Functional class was the best predictor of referral to all of these allied health professionals. Thirty-four respondents (14%) had visited a chiropractor.

Almost all the subjects interviewed (95%) had been treated with aspirin, and at least 70% had used one of the major nonsteroidal antiinflammatory agents. Sixty-four percent had received gold shots and an identical number had taken oral steroids. Thirty-seventy percent had undergone one or more orthopedic surgery procedures including joint replacement, and 70% had a joint injection at some time during their illness. As expected, the total number of drugs taken, the use of prednisone or gold, and the probability of joint surgery were significantly correlated with the duration of illness and the anatomic stage. Interestingly, functional class was not significantly correlated with the probability of using most of these therapies.

Work impacts. One hundred eighty individuals (74%) were employed at the time their disease began, in-

cluding 95% of the men and 65% of the women. The demographic and disease characteristics of this group were similar to those of the overall sample. In terms of occupation, 24% were professionals or managers, 34% held clerical or sales positions, 14% were in service occupations, and 29% were manual laborers. Ten percent of all workers were self-employed, and 24% were employed by others but had a substantial degree of work place autonomy, as measured by control over the pace and content of their work. By the time of the study, 106 subjects (59%) who had held jobs at the time their disease began were no longer working. In 82% of these cases, this change in work status was attributed by the subject directly to the presence of rheumatoid arthritis. An additional 26 subjects (14%) were working less than 40 hours per week.

The probability of disability was markedly increased in the presence of certain disease and work factors. The likelihood of disability, defined as complete cessation of work, was significantly higher in those with radiographic stage III or IV disease and those with disease durations longer than 5 years.

Two work factors, self-employment and substantial workplace autonomy, significantly decreased the probability of disability. Occupational category per se had no effect on the likelihood of disability. A multivariate analysis of disability using discriminant analysis indicated that workplace factors (68% prediction) were slightly more important than disease factors (64% prediction) in determining whether an individual would become disabled by rheumatoid arthritis. Sociodemographic factors had no important effect on work disability; the effects of age, sex, race, and education were all insignificant. Respondents who had never been married had a significantly lower disability rate than married subjects but they also tended to be younger and have disease of shorter duration. The effect of selected factors on disability is summarized in Table 1.

Financial impact. A conservative estimate of the financial impact of rheumatoid arthritis was developed by examining the income losses sustained by those subjects who were working at the time their disease began. These 180 individuals were earning an average of \$7,647 at that time (average year of onset was 1970) with an average family income of \$13,156. These respondents were thus earning an average of 69% of their family's overall income at the time their disease began. By the time of the study, there had been a significant change in this financial situation. The workers in our sample earned only 50% of what would be expected from a conservative estimate of their study-year income

Table 1. Probability of work disability in rheumatoid arthritis stratified by selected disease, demographic, income, and work variables

Variables	Stratification	Number	Probability
<i>Demographics</i>			
Age of onset	≤50/>50 years	131/49	0.57/0.63
Sex	Male/female	78/102	0.56/0.61
Race	White/other	148/32	0.58/0.62
Marital status	Never married/currently married	21/111	0.33/0.60*
Education	≤12/>12 years	117/63	0.61/0.56
<i>Disease</i>			
Duration	≤5/>5 years	76/104	0.40/0.73*
Radiographic stage	I, II/III, IV	80/100	0.49/0.67†
Joint surgery	No/yes	112/68	0.52/0.71*
<i>Income</i>			
Premorbid income	≤\$7,500/>\$75,000	110/70	0.66/0.49*
<i>Work</i>			
Occupation	Manager, sales/service, labor	93/87	0.54/0.64
Self-employment	Yes/no	18/162	0.28/0.62†
Workplace/autonomy	Great/little	43/61	0.44/0.79†
Total patients		180	

* $P < 0.05$ † $P < 0.01$

potential. Average individual earnings had dropped to \$5,235 (in inflated 1978 dollars) which accounted for only 32% of family income. A summary of the premorbid and study year financial status of disabled and employed workers is shown in Table 2.

In 134 cases (75% of the workers), the individual was earning at least \$200 less than the conservative prediction. In this group, income dropped from \$8,619 to \$3,889 (uncorrected for inflation), and this decreased their contribution to family income from 78% to 24%. Income losses were significantly related to radiographically advanced disease and longer disease duration, whereas various sociodemographic factors, including age, sex, and years of education, had no significant effect. In terms of workplace variables, the degree of workplace autonomy had a major impact ($P = 0.01$) on determining whether an individual with rheumatoid arthritis would sustain an income loss, while the occupational category of the individual and the national unemployment rate for that category proved to be unimportant.

The majority of the workers did not have enough job-related disability insurance to cover most of these income losses. Only 90 workers had policies that would provide income if they had to totally stop work because of illness, and in 59% of those cases the coverage would continue for only 6 months or less. On the other hand, the vast majority of workers had satisfactory coverage

for medical expenses. Seventy-nine percent had some form of health insurance, and 86% (69% of all workers) had "major medical" coverage.

Psychosocial impact. The most frequent psychosocial impacts were changes in marital and employment status and leisure activities. At the time of the study, 18% of the respondents who had ever married were divorced or separated, compared to a national average of 11% (15). One hundred and six workers (59%) had stopped working completely while a number of others had changed their occupation or decreased the number

Table 2. Financial impact of rheumatoid arthritis

	All workers* (N = 180)	Workers employed in study year (N = 74)	Workers disabled in study year (N = 106)
<i>Premorbid finances†</i>			
Individual earnings	\$12,277	\$13,685	\$11,295
Family income	\$21,122	\$23,973	\$19,129
% family income	69	77	64
<i>Study year finances</i>			
Individual earnings	\$ 5,235	\$11,015	\$ 1,000
Family income	\$16,089	\$19,243	\$13,887
% family income	32	63	09
Lost/expected earnings	50	08	80

* Respondents who worked at time of disease onset.

† All amounts adjusted to 1978 dollars using standard Consumer Price Index inflator.

of hours they put in each week. A large majority of the respondents (85%) reported a major change in their leisure activities. In addition to these major impacts, 18% of the subjects had changed their place of residence due to their rheumatoid arthritis, while the family members of 6% had changed employment status to compensate for the impact of illness. If the effect on leisure is excluded, 63% of the subjects experienced at least one of these major psychosocial changes as a result of their rheumatoid arthritis. Those in the bottom half of the sample in terms of predisease income status had no greater likelihood of experiencing one of these changes than a subject in the upper half of the group. However, even when work changes are excluded, those with income losses had a significantly worse psychosocial outcome ($P < 0.00$).

DISCUSSION

The results of the study draw an impressive sociomedical portrait of rheumatoid arthritis. The demographic data suggest that this group of subjects represents a reasonable cross-section of adults with this disease, and it is likely that their sociomedical profile accurately reflects the status of patients with this chronic disease. Since all subjects were being cared for by a rheumatologist, it is likely that they were receiving medical care of reasonable quality. A majority have also had at least one orthopedic and physical therapy consultation. More than half had received gold therapy or other potentially disease-modifying treatment. At the time of the survey, 70% were reported to be in the better two categories of functional capacity.

Despite this evidence of ongoing, reasonable medical care and adequate function, subjects experienced numerous socioeconomic impacts from their disease. A majority of the working subjects were fully disabled, most as a direct result of their arthritis, and most of the others had to change occupations or reduce their hours. This effect on work was found across all occupational and sociodemographic classes, indicating the pervasive effect of this chronic disease on employment. As a result of this work impact, many subjects suffered wage losses that produced major decreases in personal and family income. The importance of work was seen not only in its income effect but also in its relation to the psychosocial impacts of rheumatoid arthritis. Although most subjects experienced at least one major psychosocial change in association with their disease, those with income losses resulting from work disability fared noticeably worse.

Strauss, Engel, and others have pointed out that chronic disease affects all aspects of a patient's life (16–19). Our results provide empirical support for this view by documenting the impressive work, income, and psychosocial impacts of rheumatoid arthritis. These results generally support the findings of previous sociomedical studies of this disease (20–22). In particular, the results point out the central role played by work in terms of the increased economic and psychosocial problems associated with work disability (23). We have examined the course of work disability in rheumatoid arthritis in more detail elsewhere (24).

The ultimate goal of medical care is to improve the well-being of the patient. It is clear from this study that the prevention and amelioration of socioeconomic problems should be a major aspect of the care of an individual with rheumatoid arthritis. In too many cases, however, physicians consider such problems to be outside their area of concern or assume that the sociomedical problems will resolve themselves if the biological disease is properly treated. Unfortunately, the long-term effectiveness of available therapy is fairly limited in rheumatoid arthritis and many other chronic diseases (25,26), so that individuals with these conditions will continue to develop major socioeconomic and psychosocial problems despite the best therapy.

Physicians must be better trained and more willing to deal with sociomedical problems if they want to help their patients cope with chronic diseases. On the one hand, they must recognize the scope and the magnitude of the sociomedical problems produced by chronic disease, and on the other hand, they must realize the limitations of available medical and surgical treatments. The curricula in sociomedical sciences being developed in many medical schools may help foster this awareness.

Once physicians begin to address such problems, they need not and should not rely solely on their own skills. In many cases there are health care professionals willing and able to deal with sociomedical problems. The use of such professionals should be increased. In our study, for example, only 15% of the subjects had been referred to a social worker despite the presence of numerous socioeconomic problems. We have previously described a similar discrepancy between the utilization of medical and psychosocial services in another group of rheumatoid arthritis patients (27). It is likely that this is a common situation in other chronic diseases as well, and it serves as one example of a practice habit that might profitably be changed.

In summary, a large group of patients with a reasonably typical chronic disease, rheumatoid arthritis,

has been shown to have a large number of sociomedical problems, the most important of which appears to be work disability. The recognition of these sociomedical impacts is a necessary first step in an effort to alter the principles and practices of medical care in such a way that physicians can deal more effectively with the growing number of patients they see who have a chronic disease.

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REFERENCES

1. U.S. Department of Health, Education, and Welfare: Limitation of activity due to chronic conditions, U.S. 1974. Vital and health statistics series 10, Number 11. Washington, DC, USGPO, 1977. (DHEW Pub. No. HRA 77-1537)
2. Krute A, Burdette ME: 1972 survey of disabled and non-disabled adults: chronic disease, injury and work disability. *Soc Sec Bull* 41 (4):3-17, 1978
3. Funkenstein DH: The learning and personal development of medical students reconsidered. *New Physician* 741-755, Sept 1970
4. Barber B: Compassion in medicine: toward new definitions and new institutions. *N Engl J Med* 295:939-943, 1976
5. McKeown T: *The Role of Medicine: Dream, Mirage or Nemesis*. Princeton, New Jersey, Princeton University Press, 1979, pp 117-190
6. Strauss AL: *Chronic Illness and the Quality of Life*. St. Louis, CV Mosby, 1977
7. U.S. Department of Health, Education, and Welfare: *Work disability in the U.S.: a chartbook*. Washington, DC, USGPO, 1977. (HEW Pub. No. SSA 77-11978)
8. Weiner CL: The burden of rheumatoid arthritis: tolerating the uncertainty. *Soc Sci Med* 9:97-104, 1976
9. Masi AT, Medsger TA: *Epidemiology of the rheumatic diseases, Arthritis and Allied Conditions*. Ninth edition. Edited by DJ McCarty. Philadelphia, Lea & Febiger, 1979, pp 12-16
10. Steinbroker O, Traeger CH, Buttermann RC: Therapeutic criteria in rheumatoid arthritis. *JAMA* 140:659-662, 1949
11. U.S. Employment Service: *Dictionary of occupational titles*. Vol 2. Occupational classification and industry index. Washington DC, USGPO, 1965
12. U.S. Employment Service: *Dictionary of occupational titles, Supplement to the third edition: Selected characteristics of occupations (physical demands, working conditions, training time)*. Washington, DC, USGPO, 1966
13. Yelin EH, Nevitt M, Epstein WV: Towards an epidemiology of work disability. *Milbank Mem Fund Q* 58, 1980
14. Meenan RF, Yelin EH, Henke CJ, Curtis DL, Epstein WV: The costs of rheumatoid arthritis: a patient oriented study of chronic diseases costs. *Arthritis Rheum* 21:827-833, 1978
15. U.S. Bureau of the Census: *Statistical abstract of the United States, 1977*. Washington DC, USGPO, 1977, p 75
16. Strauss AL: *Chronic Illness and the Quality of Life*. St. Louis, CV Mosby, 1975, pp 1-9
17. Engel GE: The need for a new medical model: a challenge for biomedicine. *Science* 196:129-136, 1977
18. Spergel P, Ehrlich GE: The rheumatoid personality: a psychodiagnostic myth. *Psychosomatics* 19:79-86, 1978
19. Ehrlich GE: *Sexual problems of the arthritic, Total Management of the Arthritic Patient*. Edited by GE Ehrlich. Philadelphia, Lippincott, 1973, pp 193-208
20. Allander E: A population survey of rheumatoid arthritis: epidemiological aspects of the syndrome, its pattern and effect on gainful employment. *Scand J Rheumatol (Suppl)* 15:86-100, 1970
21. Meenan RF, Yelin EH, Henke CJ, Curtis DL, Epstein WV: The costs of rheumatoid arthritis: a patient-oriented study of chronic disease costs. *Arthritis Rheum* 21:827-833, 1978
22. Polley HF, Swenson WM, Steinhilber RM: Personality characteristics of patients with rheumatoid arthritis. *Psychosomatics* 11:45-49, 1970
23. Luft H: *Poverty and health: economic causes and consequences of health problems*. Cambridge, Ballinger, 1978
24. Yelin EH, Meenan RF, Nevitt M, Epstein WV: Work disability among persons with rheumatoid arthritis: the relative impact of disease, social, and work factors. *Ann Intern Med* 93:551-556, 1980
25. Lee P, Kennedy AC, Anderson J, Buchanan WW: Benefits of hospitalization in rheumatoid arthritis. *Quart J Med* 43:205-214, 1974
26. Katz F, Vignos PJ, Moskowitz RW, Thompson HN, Svek KH: *Comprehensive care in rheumatoid arthritis: a controlled study*. *JAMA* 206:1249-1259, 1968
27. Yelin EH, Fishbach DM, Meenan RF, Epstein WV: Social problems, services and policy for persons with chronic disease: the case of rheumatoid arthritis. *Soc Sci Med* 13:13-20, 1979