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## Rheumatoid Arthritis and Ankylosing Spondylitis in British Columbia Indians:

### Their Prevalence and the Challenge of Management

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CURRENT information regarding the prevalence of rheumatoid arthritis and Marie-Strümpell spondylitis in the Indian population of British Columbia indicates not only important similarities but also intriguing differences from reported prevalence rates of these diseases in other populations of the world.

#### RHEUMATOID ARTHRITIS

Most of the few reported epidemiological population studies have been set up to determine the point prevalence of arthritis in a known population 15 years of age and over. A defined population is usually interviewed and examined. Predetermined radiographs, including the hands, feet and often the neck, are taken and serum rheumatoid factors are determined. The study is usually carried out over a brief period and the results indicate the amount of arthritis in a population at that point in time.

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The single published study on the prevalence in Canadian Indians is a point prevalence study of this type.<sup>1</sup> The sample consisted of 492 Haida Indians aged 15 and over who were on the Reserve Band list and permanent residents of two major reservations in the Queen Charlotte Islands. Four hundred and thirty-six adults were studied, representing a completion rate of 88.6%. Four cases of definite rheumatoid arthritis satisfying the criteria of the American Rheumatism Association (A.R.A.)<sup>2</sup> were found and five cases were designated as probable. For individuals over 35 years with definite disease a point prevalence of 1.4% was established which is identical with that found in Wensleydale, England, and similar to that reported in other parts of Britain, Germany, Jamaica and the United States of America.<sup>3</sup> The United States studies include Blackfeet Indians in Montana and Pima Indians in Arizona. We are not aware of any studies of the point prevalence of rheumatoid arthritis in children, but the incidence is much lower than in adults. Estimates have been made on the basis of numbers referred to particular hospitals or clinics in relation to the total populations they serve. Laaksonen<sup>4</sup> reports an annual incidence between 1956 and 1961 of 3.8 new cases per 100,000 of the total population under 15 referred to the Rheumatism Foundation Hospital in Turku, Finland. Our experience with arthritis in Indian children in British Columbia is of interest in this regard.

The total Indian population of the province is about 43,250, of whom 20,000 are under 15 years of age.<sup>5</sup> From 1960 to 1967 an annual average of two Indian children with juvenile rheumatoid arthritis were referred to the children's program of the Canadian Arthritis and Rheumatism Society (C.A.R.S.) in Vancouver, which would represent 10 per 100,000—in excess of Laaksonen's estimate. The topography and population distribution patterns in Finland and British Columbia bear some similarity and in neither situation is it likely that all affected children, particularly those from isolated northern communities, are referred to the centre in the south.

In a recent review of experience in our children's program it has been pointed out that, whereas the proportion of Indians to the total child population of British Columbia is 3.3%, Indian children make up 18% of children seen in this clinic population.<sup>6</sup> A higher proportion of the Indian children were judged to be severely affected, 60% having poor functional capacity (Grades III and IV<sup>7</sup>) as opposed to 28% of white children in these two categories.

#### ANKYLOSING SPONDYLITIS

The incidence of Marie-Strümpell spondylitis was found to be much higher than expected in Haida Indians of the Queen Charlotte Islands.<sup>8</sup> Of 436 respondents, 10 had unequivocal spondylitis (2.3% of the total population or 4.2% of the males studied). This prevalence is remarkably high in comparison with other reports quoted by the authors indicating a prevalence of no more than 0.3%. A further study was conducted by the same authors in 1964<sup>9</sup> and included radiographs of the sacro-iliac joints of all males; sacro-iliitis was found in 9.5%, as compared with 2.6% reported in the Blackfeet Indians of Montana and 3.9% in the Pima Indians of Arizona.<sup>10</sup> It seems likely from these figures that there is a large reservoir of ankylosing spondylitis in the Haida Indians. Whether or not this applies to the other coastal Indians is as yet unknown.

#### SOCIAL FACTORS AND MANAGEMENT

Many Indian reservations are geographically remote and the basic treatment measures currently used to maintain optimal health and function over a long period are simply not available. These include such facilities as physiotherapy, occupational therapy, provision for self-help devices and adaptation for the disabled at home and at work. In addition, current drugs, often potent, require careful monitoring which

is difficult to achieve without close medical supervision. Currently, many Indian patients with rheumatic diseases are referred to C.A.R.S. Travelling Consultation Clinics. Although initial treatment may be provided locally, patients are often referred to the C.A.R.S. Arthritis unit in Vancouver when disease is severe or when disability threatens. Here evaluation is carried out, goals are established and management is recommended. Long-term in-patient management for both adults and children may be necessary but beds for adults are few, and in the case of children immediate benefits from hospitalization must be carefully weighed against the harmful effect of separation from home and family. After discharge, follow-up care must be arranged. Although this can be provided satisfactorily on an ambulatory basis for patients living close to the larger communities, a major gap in services can be expected when a patient is transferred from an intensive management unit to a remote area. In some districts home advice and functional aids may be provided by travelling occupational therapists and physiotherapists,\* and public health nurses may offer home-visiting assistance. Follow-up management in other instances, however, is extremely difficult and the patient who has made substantial gains under intensive therapy is in danger of regressing unless supervised. In some instances relocation of the individual within a community having good treatment facilities is possible and retraining for an occupation appropriate to the disability can be arranged. In other instances social factors militate against ideal management. These problems are illustrated in the following case summaries.

CASE 1.—H.G. first suffered symptoms of rheumatoid arthritis at the age of 20. At this time he was engaged in logging while living on a remote reserve. By age 26 his knees, ankles and wrists were severely affected and he could no longer work. He underwent intensive rehabilitative therapy at the C.A.R.S. Arthritis unit in Vancouver and as part of his program underwent synovectomy in both knees. As the result of several months' treatment he became capable of some work but was clearly unable to resume heavy labour. No alternative occupation was available on the reserve. With the support of the various agencies he completed a Grade 10 upgrading course and was subsequently placed in an "on the job" training situation. He is now self-supporting, deriving his income from repairing appliances, and lives in an urban setting fairly close to a rehabilitation facility from which his ongoing therapy can be supervised.

\*In British Columbia C.A.R.S. provides a Travelling Occupational Therapy Van Service and employs a number of physiotherapists who are based in hospitals throughout the province.

CASE 2.—E.W. contracted rheumatoid arthritis at 9 years of age, with onset in the knees followed by generalized polyarthritis. She lived by a lake remote from any hospital, 400 miles from Vancouver. At age 11 there were severe knee contractures, and prolonged rehabilitation, including a surgical procedure on both knees, was necessary. Over the next few years she attended an Indian residential school with intermittent periods in hospital, and went home to the reservation each summer. She returned from these holidays anemic, weak and underweight. She had progressive disease and at age 17 was again hospitalized for intensive rehabilitative management and had a second operation on the knees. For a time she was markedly improved, but later became depressed and desperately homesick. Her parents wanted her at home and despite deterioration of her general condition she returned to the reserve. She currently reports progressive disability and has difficulty adjusting to the food and general living situation at home.

**Summary** It would appear that rheumatoid arthritis is as common in the Indian population as in other populations studied. There is some possibility as yet unproved that juvenile rheumatoid arthritis occurs more commonly in British Columbia Indians. There is a very high rate of ankylosing spondylitis in Haida Indians. The care of such long-term and potentially disabling diseases on the remote reserve presents formidable difficulties and the physician is frequently faced with a dilemma concerning the provision of optimal medical management and the realization that this can have no lasting success unless continuing support is available. Rehabilitation and maintenance facilities exist only in larger communities, and social disruption may be the price paid for good treatment. In some instances resettlement in communities with facilities for proper rehabilitation is possible, and this may be the best solution to management. However, a sincere attempt must be made with the help of the family and social agencies to achieve a balance between the physical indications for intensive medical or surgical management and the spiritual needs

of the Indian patient who may never be happy away from his own people.

**Résumé** Il semble que l'arthrite rhumatoïde soit aussi fréquente chez les Indiens que dans les autres populations étudiées. Il est possible, quoique non encore démontré, que les Indiens de Colombie-Britannique soient particulièrement sujets à l'arthrite rhumatoïde juvénile. La spondylite ankylosante est extrêmement répandue parmi les Indiens Haida. Le traitement de ces maladies, qui sont longues et peuvent être causes d'infirmités, se heurte, dans les réserves isolées, à d'énormes difficultés et le médecin se trouve souvent placé devant un dilemme quant au choix du mode de traitement, sachant que les meilleurs soins ne peuvent avoir d'effets durables si le malade n'est pas suivi. Seules les agglomérations d'une certaine importance sont équipées pour la réadaptation et les traitements d'entretien, et le déracinement peut être le tribut à un traitement efficace. Dans certains cas, il est possible de rétablir le malade dans une localité pourvue d'un établissement de réadaptation et ce peut être la meilleure solution du point de vue thérapeutique. Mais il faut à tout prix essayer, avec l'aide de la famille et des organismes d'assistance sociale, de trouver le juste milieu entre les exigences matérielles d'un traitement médical ou chirurgical intensif et les besoins spirituels de l'Indien malade qui risque de n'être jamais heureux loin des siens.

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