Editorial Comment

Rheumatic fever is prevalent in many developing countries of Africa, Asia, Latin America and the Caribbean, often starting at earlier ages, and with more severe carditis and higher mortality than in developed countries. In the latter, acute rheumatic fever and chronic rheumatic cardiopathy are virtually nonexistent. In developing countries, although their frequency is gradually diminishing, they are more heavily concentrated in the lower socioeconomic strata of the population. Hence, national averages do not reflect the wide socioeconomic disparities that exist in these countries. The lack of systematic control programs and adequate epidemiological surveillance systems makes it impossible to detect the local variations concealed by a national average.

The present report illustrates the early detection of an unusual rise in the number of cases of acute rheumatic fever in an area of metropolitan Santiago that has a control program. Hence, it represents an example of efficient and timely use of information for action. The whole point of epidemiological surveillance lies in the collection of information and in its proper use. It is hoped that a thorough study of this epidemic outbreak of acute rheumatic fever will help shed light on the rheumatogenic potential of the beta-hemolytic streptococcus strains prevalent in that area, and particularly whether the cases in this outbreak are mostly new or due to recidivation. In the former event, they could be local variations in the natural history of the disease and, in the latter, the most plausible explanation would necessarily have to be sought in quantitative or qualitative deficiencies of secondary prevention in the population at risk.

Registration of Chronic Disease in Canada: An Overview

These general remarks on disease registration in Canada were published as a preface to more detailed reports; they bring up to date a previous review *(1)*. Most of the literature on registries is focused on specific diseases and is too extensive for complete review. Some authors, however, have provided a more global perspective *(2-6)*. Recent reviews relating to particular disease groups include cancer *(7-10)*, congenital malformations *(11)*, and rheumatic diseases *(12)*.

Various definitions and typologies of registries have been proposed *(5)*. According to Weddell *(3)*, "the principal objectives of registries can be summarized as collating information collected from defined groups over time, which may be used in the prevention or treatment of disease, the provision of after-care, the monitoring of changing patterns of disease and medical care, and the evaluation and planning of services."

Weddell also points out that "registers, designed to collect information on one specific topic, must be distinguished from master patient files and record linkage systems, which provide means to collect, store and retrieve information on many topics not predetermined or limited in their scope." This is an important distinction which leads to the question as to whether it is necessary to have a separate registry for each disease rather than a single system in which each individual is followed and all disease episodes recorded. The latter approach has long been anticipated as a spin-off from centralized health insurance *(13)* but is slow in coming. However Roos and Nicol *(14)* have demonstrated that it is feasible in the Canadian context.

It is sometimes claimed that the patients themselves benefit from being included in a disease registry because of more efficient follow-up. This may be true in some special cases (e.g. Pap smear, handicap) but would be difficult to support in general, since it presupposes that follow-up does more good than harm which needs to be shown. Nor does the individual physician have much to gain from a disease registry unless he/she is contributing enough patients to make survival analysis worthwhile. Clearly most, if not quite all, the benefit is epidemiological, in the broadest sense of the term, and it is difficult to maintain the interest of individuals in an exercise for the public good, however well-intentioned they may be. Population based registries cannot rely on notification by the physician but must have access to hospital, laboratory and death records to achieve completeness. Making disease notification obligatory by law does not help, as we know from infectious disease notification. However Enterline *et al. (15)* have

studied cancer reporting laws in relation to cancer registration in the United States. They found "that the existence of a state cancer reporting law did not ensure the creation of a cancer reporting system and, conversely, many registration systems existed in states having no reporting laws. However, states with reporting laws were more likely to have a registration system than states without such laws." They stress that "provision should be made in each law to provide for access to disaggregated data by qualified researchers. Without such access, the utility of a cancer surveillance data base is minimal."

While it is true that population-based disease registries are useful as a source of cases for case-control studies, and as the end-point for cohort studies and as a start-point for survival analysis, surely their "raison d'être" must be to provide estimates of disease incidence (or prevalence at birth in the case of congenital disease). If epidemiology is the study of diseases in populations and the essence of science is measurement, then if epidemiology is to be a science in its own right, and not a branch of pathology, measurements of disease incidence are indispensable. We cannot be content with mortality as a proxy for incidence.

If an unduplicated count of all new cases of disease in a defined population at risk is the primary goal, what other information should be collected? Would known risk factors other than age and sex be included, for example, smoking or occupation? If the prevalence of such factors in the general population is known from a census or health survey, then differences in incidence by time or place can be adjusted for such factors. Should the incidence cases be followed up to ascertain disability and death? Some epidemiologists discount measures of survival, pointing out that the only valid method of comparing treatments is a randomized controlled trial. This is true, but treatment is not the only factor influencing survival, and is there not a place for a descriptive epidemiology of survival as well as incidence?

But the most important question is: who will pay? Disease registration is expensive and research-funding agencies are loath to assume a long-term burden. As Adelstein *(16)* has pointed out, the first disease surveillance system, the Bills of Mortality, was based on fear of the plague, and was paid for by wealthy subscribers who would move out at the first sign of an epidemic. Fear was probably an important factor in raising public support for infectious disease notification and, more recently, reporting of congenital malformations and AIDS. Registration of some chronic diseases such as tuberculosis, cancer and end-stage renal disease has been a by-product of special treatment. How can public support be mobilized for registration of other important diseases such as cardiovascular disease, diabetes, arthritis and chronic neurological diseases, where contagion is not an issue and treatment is diffuse? Must we rely on charity?

(Source: Article by G. B Hill, *Chronic Diseases in Canada* 6(4):72-73, 1986.)

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Editorial Comment

Although some of the elements described in this article are only applicable to industrialized countries such as Canada, it has been considered of interest to publish this discussion for it presents criteria that are valid for all countries in the Region of the Americas. It is also an interesting complement to the discussion on cancer registries appearing in the *Epidemiological Bulletin*, Vol. 6, No. 6, 1985.